

ARTHRITIS: A NATIONAL EPIDEMIC

HEARING

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON HEALTH, EDUCATION,

LABOR AND PENSIONS

UNITED STATES SENATE

ONE HUNDRED EIGHTH CONGRESS

SECOND SESSION

ON

EXAMINING THE CURRENT AND FUTURE IMPACT OF ARTHRITIS, FOCUSING ON PREVENTING, CONTROLLING AND CURING ARTHRITIS AND THE OPPORTUNITIES PUBLIC HEALTH HAS TO MAKE A DIFFERENCE IN REDUCING THE PAIN AND DISABILITY ASSOCIATED WITH ARTHRITIS, INCLUDING S. 2338, TO AMEND THE PUBLIC HEALTH SERVICE ACT TO PROVIDE FOR ARTHRITIS RESEARCH AND PUBLIC HEALTH

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JUNE 8, 2004
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Printed for the use of the Committee on Health, Education, Labor and Pensions



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ARTHRITIS: A NATIONAL EPIDEMIC

TUESDAY, JUNE 8, 2004

U.S. SENATE,
SUBCOMMITTEE ON AGING,
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Washington, DC.

The subcommittee met, pursuant to notice, at 10:05 a.m., in room SD-430, Dirksen Senate Office Building, Hon. Christopher S. Bond (chairman of the subcommittee) presiding.

Present: Senators Bond, Mikulski, and Murray.

OPENING STATEMENT OF SENATOR BOND

Senator BOND. Good morning. The Subcommittee on Aging of the Senate Committee on Health, Education, Labor and Pensions will come to order. We welcome you all here today to discuss arthritis, the disease and the cures.

With more than 100 different forms, arthritis is one of the most widespread and devastating health conditions in the United States. Nearly 70 million, or 1 in every 3, American adults suffer from arthritis or chronic joint symptoms, and 300,000 children live with the pain, disability, and emotional trauma caused by juvenile arthritis.

The number of Americans who live with arthritis will grow as the number of us older Americans continues to increase dramatically in the next few decades. As the leading cause of disability in the United States, arthritis is a painful and debilitating chronic disease affecting men, women, and children alike. Arthritis has no boundaries.

Simple daily tasks, like brushing teeth, pouring a cup of coffee, or even getting out of bed, become excruciating obstacles for millions of people who suffer from the disease. I watched firsthand as my mother suffered increasing arthritis pain throughout the last years of her life. She believed at the time that bedrest was the best way to deal with it. She held out the hope that perhaps when the arthritis fused in her back it might bring some relief from the pain. Unfortunately, it did not.

As a faithful son, obviously, I inherited the arthritis and then made the mistake of playing rugby in college. As a result, I have had two neck operations, a fusion of two cervical vertebrae, brand new replaced thumb joint, and a new hip, which enables me to set off the alarms at airport security like a penny arcade.

But to move from the specifics and our small problems to the general, the impact of the disease on our health system is also dramatic. Arthritis results in three-quarters of a million hospitaliza-

tions, 44 million outpatient visits, and 4 million days of hospital care every year, according to the Centers for Disease Control and Prevention. The CDC estimates that the annual cost of medical care for arthritis is \$51 billion, and the annual total cost, including lost productivity, exceeds \$86 billion. Early diagnosis, treatment, and appropriate management of arthritis are critical to controlling symptoms and improving quality of life.

To address these issues, Senator Kennedy and I have introduced S.2338, the Arthritis Poverty, Control, and Cure Act, earlier this year. This bill would: No. 1, improve coordination among Federal agencies and the public regarding the Federal investment in arthritis research and public health activities through a National Arthritis and Rheumatic Diseases Summit; No. 2, accelerate research that would lead to improved treatments and a cure for juvenile arthritis; No. 3, invest in a nationwide public health initiative designed to reduce the pain and disability of arthritis through the early diagnosis and effective treatment of the disease; and, No. 4, ensure kids with arthritis have access to specialty care by addressing the nationwide shortage of pediatric rheumatologists.

We have a responsibility to look for solutions to this issue in a comprehensive manner, and I think this bill can make a real difference in the lives of the millions of Americans, both young and old, who suffer from this debilitating disease.

Today, we are honored to have before the subcommittee a distinguished panel of doctors, researchers, patients, and advocates to discuss arthritis, to tell us how we can improve the bill, what we need to do differently, what we should add to it, because the burden this disease places on our society and economy, the progress being made toward the understanding, diagnosis, treatment, and prevention of arthritis for both children and adults is an appropriate subject for this hearing. We look forward to learning from our witnesses.

Now it is my great pleasure to turn to my good friend and colleague, the Senator from Maryland, Senator Barbara Mikulski.

Senator Mikulski.

OPENING STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. Good morning, Senator Bond, and to our witnesses, and to all who are here today

First of all, I want to thank you, Senator, for holding this hearing on arthritis so that we could get the latest updates on both research as well as a navigational chart on where we need to proceed.

I also want to acknowledge your leadership in introducing, along with our colleague, Senator Kennedy, the Arthritis Prevention, Control, and Cure Act of 2004. I am proud to be a cosponsor of that. Again, it is the spirit of bipartisanship that we need, you know, when we have to find cures or the ability to manage disease and so on. It does not really matter what party you are. It matters that you have arthritis or you have Alzheimer's, as our dear President and my father had, et cetera. I know that you saw the individual pain of both your mother and even had those challenges yourself.

So we need to let people know we are on their side, and I want to tell our witnesses we are really looking forward to getting the best of the advice that they had to offer. I would also like to acknowledge that there are Marylanders here, Senator Bond—Jan Thompson, who is the president of the Maryland Chapter of Arthritis, and Brenda Crabbs, who is the past president and some others—who are here to say hello to you this morning. We welcome you to listen and then to get your advice, because I believe the people in the field and the people who are the most affected should have the most to say.

Senator Bond has articulated already the many facts and data about how this strikes people, from osteoarthritis to rheumatoid arthritis, lupus, which affects so many women, and, of course, juvenile arthritis. The activities of daily living are just challenged when you are dealing with this, and what we need to do is to find out how we can both manage what people have, to either find the cure or either those other issues that could help them live a life full of vibrancy.

What strikes me in looking at all the data and listening to letters from my own constituents is that arthritis has no boundaries on gender, race, or age. Often we think of it as something in an older person, but yet 300,000 children in our country are afflicted by it, which will impact their entire lives. This is a disease that affects women and it affects men. It affects black, white, and other color, which shows that it is an all-American disease. So we have to have an all-American effort.

I recall back even 20 or 30 years ago, there was so little available. What they had was what they called “the gold treatment.” I don’t know if your mom did that, Senator Bond, but remember where you would go and get the infusions of gold, and somehow or another the metallic impact eased pain and enabled more agile functioning of limbs.

Now we are making other successful strides in treatment, research, and prevention, but we need to do more. With the boomers coming on age, this is also going to be an increasing challenge.

I have been glad to work with Senator Bond as a cosponsor of this and also to work for initial funding for the Arthritis Plan, and also now I am looking at a \$5,000 tax credit that would help people with home health care, prescription drugs, specialized day-care where children in need might be impacted. But today is not to listen about what I have got to say; it is to listen to what you have to say. So just in the real spirit of welcoming to an all-out, all-American effort, we just want to say good morning and look forward to hearing from you.

[The prepared statement of Senator Mikulski follows:]

PREPARED STATEMENT OF SENATOR MIKULSKI

INTRODUCTION

Thank you to Chairman Bond for holding this hearing on arthritis. This issue is very important, and I thank you for your leadership.

FACTS

Seventy million Americans are afflicted with arthritis today. It is the number one cause of disability in the U.S. among Americans over the age of 15. There are over 1 million people living with arthritis in my home State of Maryland. Arthritis limits every day activity for over 7 million Americans.

Arthritis and the disability it causes creates huge burdens for individuals, their families, and the Nation. In 1995, arthritis cost more than \$22 billion in direct medical costs, and over \$82 billion in total costs.

People who suffer from prevalent forms of arthritis—such as osteoarthritis, rheumatoid arthritis, lupus, and juvenile arthritis—struggle with everyday activities like getting dressed, brushing their teeth, and pouring a cup of coffee.

They may have to quit their job or change jobs because arthritis prevents them from doing jobs.

WHY ARE WE HERE TODAY?

Our hearing today is titled Arthritis: A National Epidemic. Our witnesses will provide a human face for arthritis. The people who live with arthritis and the impact it has on them and their families.

Arthritis knows no boundaries of gender, race, or age and affects nearly 300,000 children and afflicts both women and men. However, it is more prevalent in women.

We need to hear from advocates, CDC, and researchers to see what can be done to prevent, treat, and cure arthritis.

WHERE ARE WE HEADED?

In 1948, there was little or no money being spent on arthritis research. The medical community and the public felt that there was nothing that could be done about arthritis.

Today, we know that is not true. We are making successful strides in treatments, research, and prevention. In 1999 the National Arthritis Action Plan was published. The plan is a true public health strategy for arthritis, guiding the use and organization of our Nation's health resources to combat the greatest single cause of chronic pain and disability among Americans. We must continue to focus on chronic diseases that many Americans will face. Arthritis is one of those diseases.

Baby Boomers are now at prime risk for arthritis. More than half of the people affected by arthritis are under age 65. As the population ages, the numbers will increase dramatically.

BAM RECORD

I'm proud to be on the side of arthritis patients and their families by increasing prevention, providing access to treatments, and supporting family caregivers; co-sponsor of the Bond/Kennedy arthritis bill; secured initial funding of \$10 million for the National Arthritis Action Plan; and worked to increase this funding.

I supported Medicare coverage of self-injectable drugs that help arthritis patients, sponsoring a tax credit of up to \$5,000 to help

reduce financial burden on family caregivers caring for loved ones with chronic conditions.

CLOSING

I look forward to hearing from our witnesses today, to learn how arthritis impacts the daily lives of adults and children; to discuss the current research that is being done on arthritis; and to get up-to-date information about how this disease impacts our society today and in the future with the aging Baby Boomer population. They are speaking for the millions of people who live with arthritis every day.

Senator BOND. Thank you very much, Senator Mikulski, and I join with you in that welcome and tell you that we are very fortunate to have two outstanding panels. Their full biographies will be entered in the record. I would tell our witnesses that we will make their full statements available. We will include those in the record for all of our colleagues and staff to read, and we ask that you summarize your opening presentation so we will have some time for questions.

Our first witness is Dr. Joe Sniezek, a medical epidemiologist and chief of the Arthritis Program at the Centers for Disease Control and Prevention in Atlanta. He leads the CDC's public health efforts to implement the National Arthritis Action Plan: A Public Health Strategy, through the expansion of public health science and the development of State-based public health practice.

Our second witness is Dr. Susana Serrate-Sztejn, chief, Rheumatic Diseases Branch Extramural Program at the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health, where she directs the newly created program of genetics and clinical studies within the Rheumatic Diseases Branch.

Thank you very much for being here.
Dr. Sniezek.

STATEMENT OF JOE SНИЕZEK, M.D., DIRECTOR, ARTHRITIS PROGRAM, CENTERS FOR DISEASE CONTROL AND PREVENTION

Dr. SНИЕZEK. Thank you, Mr. Chairman, Senator Mikulski, for the opportunity to address an important health problem in our society—that of preventing, controlling, and curing arthritis.

Senator MIKULSKI. Doctor, pull up the mike.

Dr. SНИЕZEK. Is it on?

Senator BOND. Is the little red light on?

Dr. SНИЕZEK. Yes, it is.

Senator BOND. It is amazing how we can go to the moon, but we still have problems figuring out the—

[Laughter.]

Dr. SНИЕZEK. Thanks. In my remarks today, I would like to focus on the impact of arthritis in the United States and the opportunities public health has to make a difference in reducing the pain and the disability associated with arthritis. Many of our efforts are guided by the "National Arthritis Action Plan: A Public Health Strategy," which was published in 1999. Our health priorities for

the Nation, “Healthy People 2010,” now include arthritis objectives for the very first time.

Arthritis comprises over 100 different diseases and conditions. The most common are osteoarthritis, gout, fibromyalgia, and rheumatoid arthritis.

In 2001, 49 million adults reported a doctor had told them they had arthritis, nearly one of every four adults—making it one of our most common chronic conditions. An additional 21 million Americans reported chronic joint symptoms that may be arthritis, but have yet to be told by a physician they have arthritis. In the next 25 years, as our population ages, CDC estimates that 71 million adults will have arthritis, including a doubling of the number among those adults over the age of 65. This does not take into account the ongoing obesity epidemic in America, which may significantly contribute to the future prevalence of arthritis.

Arthritis and its related disability cause an enormous burden for the people who have arthritis, their families, and society. Arthritis is the most frequent cause of activity limitation in America; more than 8 million citizens are limited in some way because of arthritis. CDC research has shown that each year 750,000 hospitalizations and 36 million outpatient medical care visits occur because of arthritis. In 1997, arthritis cost more than \$51 billion in direct medical costs and another \$35 billion in lost productivity. No doubt, these numbers will increase dramatically as our population ages and the number of people with arthritis increases.

CDC is bringing a population-based focus, knowledge of what works, and making links to the clinical community. CDC is using its ability to evaluate health promotion programs and identify those that work, knowledge of the public health network, and the ability to work with States and communities to implement programs.

We think the following items are critical to address arthritis:

We need to increase early diagnosis and appropriate medical management of arthritis.

We need to promote healthy lifestyles. Medical treatment alone is not sufficient. For example, physical activity is beneficial for people with arthritis.

We need to increase the use of disease self-management strategies. We have a program that teaches people with arthritis to better manage their disease. It has been shown to decrease pain and decrease costs. Yet it is not readily available and few people take it.

To address these needs, we need to increase awareness. Market research conducted by the Arthritis Foundation shows that many people are not aware of the available programs that improve the quality of life.

We need to increase the availability of programs. There are simply not enough programs in our toolbox, and those that we have are not readily available.

We need to increase accessibility and discover how best to reach people with arthritis.

CDC works closely with the Arthritis Foundation, the voice for people with arthritis and their families now for 50 years.

A core activity of the CDC Arthritis Program has been to fund State health departments to address arthritis. We currently fund programs in 36 States. For example, Illinois is increasing the availability of evidence-based arthritis physical activity programs in five counties, representing rural and underserved populations. These arthritis-specific interventions improve function and reduce pain, but are scarce in rural and underserved areas.

CDC is working to identify and evaluate promising approaches. For example, the People with Arthritis Can Exercise Program, developed and disseminated by the Arthritis Foundation specifically for people with arthritis, is currently being evaluated at the Universities of Missouri and North Carolina. This program teaches exercises to reduce pain and improve the ability to move. Pilot results are promising.

CDC and its partners are also working to reach Americans with arthritis through mass media, specifically radio, newspapers, and displays at local stores. CDC developed a marketing campaign to promote physical activity among people with arthritis. The campaign was designed to reflect a major motivator for people with arthritis. What they are most seeking is pain relief. This research led to the development of the marketing campaign, Physical Activity: The Arthritis Pain Reliever. This campaign is currently being used by 35 of the 36 State health departments who receive arthritis funding from CDC.

I thank the committee for its leadership and commitment to the health of our Nation and the interest in people affected by the epidemic of arthritis. Great progress has been made. We have a national plan that is catalyzing activities in both the public and private sectors. We need to continue our work to identify promising approaches, develop new approaches, and put science into action, getting programs that work out to the people who need them.

Thank you.

Senator BOND. Thank you very much, Dr. Sniezek.

[The prepared statement of Dr. Sniezek follows:]

PREPARED STATEMENT OF JOE SНИЕZEK, M.D., M.P.H.

Thank you, Mr. Chairman, Members of the Committee, for the opportunity to address an important health problem in our society—that of preventing, controlling and curing arthritis.

The National Arthritis Act of 1974 (Public Law 93-640) as enacted in 1975 has largely been successful in promoting basic and clinical arthritis research and establishing Multidisciplinary Clinical Research Centers. Arthritis is a large problem that is getting larger as our population ages. The public health efforts called for in the 1974 Act have only recently been initiated. *The National Arthritis Action Plan: A Public Health Strategy* was published in 1999. Our health priorities for the Nation, *Healthy People 2010*, include arthritis objectives for the very first time.

In my remarks today, I would like to focus on the impact of arthritis in the United States and the opportunities public health has to make a difference in reducing the pain and the disability associated with arthritis. I would also like to highlight a few of our activities: an example from one of our state-funded arthritis programs; a research program examining the incidence and progression of arthritis; and, a health communications campaign designed to increase physical activity among persons with arthritis.

IMPACT OF ARTHRITIS: TODAY AND IN THE FUTURE

Arthritis comprises over 100 different diseases and conditions. The most common are osteoarthritis, gout, fibromyalgia, and rheumatoid arthritis. Common symptoms of arthritis include pain, aching, stiffness and swelling. Some forms of arthritis,

such as rheumatoid arthritis and lupus, affect multiple organs, and associated with premature death.

In 2001, 49 million adults reported a doctor had told them they had arthritis; nearly one of every four adults—making it among the most common health problems in the United States. An additional 21 million Americans reported chronic joint symptoms that may be arthritis, but have yet to be told by a physician they have arthritis. In the next 25 years as the population ages, CDC estimates that 71 million adults will have arthritis, including a doubling of the rate among adults over age 65. This is likely a conservative number, since it does not take into account the ongoing obesity epidemic in America, which may significantly contribute to the future prevalence of arthritis.

Although rarely discussed, arthritis causes over nine thousand deaths each year. Most notable, is the fact that arthritis-related mortality disproportionately affects women and minorities. For example, systemic lupus deaths show marked age, sex, and race-specific disparities with the highest death rates occurring among working-age, black women.

Arthritis and its related disability cause an enormous burden for the people who have arthritis, their families and society. Arthritis is the most frequent cause of activity limitation in America; more than eight million citizens are limited in some way because of arthritis. Arthritis is also a significant cause of work disability, especially for persons with inflammatory arthritis, such as rheumatoid arthritis, of which, as many as 30 percent may be work disabled. Each year, 750,000 hospitalizations and 36 million outpatient medical care visits occur because of arthritis. Arthritis is costly to society and individuals. In 1997, arthritis cost more than \$51 billion in direct medical costs and another \$35 billion in indirect costs. No doubt, these numbers will increase dramatically as our population ages and the number of people with arthritis increases.

We know other things about people with arthritis. People with arthritis:

- Are older, more often female, and have a much poorer quality of life.
- Are more likely to be overweight or obese, which is associated with further progression of disease and, given the obesity epidemic, means even more people affected in the future.
- Are less physically active, which is associated with higher medical costs.
- Often don't discuss their joint symptoms with their doctors, resulting in delayed diagnosis and greater progression of disease. 21 million Americans report joint pain but have not been told they have arthritis.
- Are not receiving existing interventions, such as counseling to increase physical activity, achieving a healthy weight, and learning about self-management.

THE ROLE OF PUBLIC HEALTH IN ARTHRITIS

CDC has identified the following critical priorities to address arthritis:

- *Increase early diagnosis and appropriate medical management of arthritis.*—Although there is no cure for most types of arthritis, early diagnosis and appropriate management is important, especially for inflammatory types of arthritis. Early targeted therapy for rheumatoid arthritis had been shown to decrease joint destruction and improve outcomes.

- *Promote healthy lifestyles.*—Medical treatment alone, however, is not sufficient. Public health activities that reach broad population groups with arthritis are needed. Our challenge is to both identify and implement effective strategies to improve the health of entire population segments. Only since 1990, have the benefits of physical activity among people with arthritis been appreciated. Prior to 1990, people with arthritis were told by their physicians to rest their joints. Evidence now exists that shows physical activity is beneficial for most types of arthritis, can improve health AND function, and improve symptoms.

- *Increase the use of disease self-management strategies.*—Programs that teach people with arthritis to better manage their disease and optimize function can reduce both pain and health care costs. There is a very robust science base that demonstrates the positive impacts of participation in the Arthritis Self Help Course—participants report a 20 percent decrease in pain, and a 40 percent decrease in physician visits, even 4 years after course participation. A companion course, the Chronic Disease Self Management Program, has also been developed and has demonstrated positive impacts among people with a variety of chronic conditions including arthritis, heart disease, lung disease and diabetes. Less than 1 percent of Americans with arthritis who could benefit participate in such programs. Programs are not readily available in all areas.

Reducing arthritis-related disability will benefit our aging population in America. In 7 years, the leading edge of the baby-boomers will reach age 65. Many older

Americans, those most likely to have arthritis and to be limited by arthritis, may need to or wish to work longer. We will need to better understand how we can reduce arthritis-related disability and how older Americans can be accommodated in the workplace so that they can remain active and, if they choose to be, employed. This aging trend will have enormous implications for our society.

CDC and the public health community in our States and communities have a continued role to play in bringing the benefits of prevention to persons with arthritis. Public health brings the focus on population-based approaches to health, the knowledge of what works, and links to the clinical community. What CDC brings to the table is its well-recognized scientific expertise, long-standing experience in prevention research, the ability to evaluate health promotion programs and identify those that work, knowledge of the public health network and the ability to work with States and communities to implement disease prevention and health promotion programs, and unique surveillance capacity to better guide programmatic efforts.

Priority areas to address:

- *Awareness.*—Market research conducted by the Arthritis Foundation showed that many people are not aware of the available programs that improve the quality of life for people with arthritis.

- *Availability.*—There are simply not enough programs available and we need to expand the toolbox of programs.

- *Accessibility.*—In addition to expanding the number and type of existing interventions available, we need to discover how best to reach people with arthritis.

CDC works closely with the Arthritis Foundation, the voice for people with arthritis and their families for more than 50 years. The Arthritis Foundation recognizes the need for health promotion strategies for people with arthritis that are tested and proven effective. CDC's strength is its ability to demonstrate the effectiveness of an intervention strategy or program and help States and communities put it into practice.

The growing evidence for the benefits of healthy behaviors (physical activity and weight control) and disease management strategies for people with arthritis must be shared and implemented widely in public health practice. CDC can, through its leadership role in the public health community, make sure that the growing body of evidence that we can improve the quality of life among people with arthritis is applied through public health practice and supported by clinical medical practice.

CURRENT CDC EFFORTS

Despite the enormous burden of arthritis, public health efforts for arthritis are fairly new. Prior to 1998, we are aware of only two States that had organized activities addressing arthritis: Missouri and Ohio. There was no national public health plan for arthritis and arthritis had never been made a priority in our national health objectives. CDC, too, had limited efforts.

The National Arthritis Action Plan: A Public Health Strategy was developed by CDC, the Association of State and Territorial Health Officials, and the Arthritis Foundation with the help and input of 90 other organizations to address this large and growing problem. This landmark plan recommends national, coordinated efforts to reduce pain and disability and improve the quality of life for people with arthritis. This plan forms the foundation for CDC's arthritis efforts.

The primary goal of the CDC Arthritis Program is to improve the quality of life for people affected by arthritis—decreasing the pain and disability that often accompany arthritis. Since 1999 when CDC received its first ever appropriation for arthritis, CDC has made progress.

Support to States

A core activity of the CDC Arthritis Program has been to fund State health departments to develop activities to address the burden of arthritis in their State. CDC currently funds Arthritis Programs in 36 State health departments. At present, 35 states have active coalitions which guide activities and share responsibility for reducing the burden of arthritis, and 31 States have published plans for reducing the burden of arthritis in their State. Partnerships and joint activities with the Arthritis Foundation are key features of these State programs. Prior to 1999, only 10 States had gathered data to measure the number of people with arthritis in their State; in 2001, all 50 States and the District of Columbia measured how many people with arthritis live in their State. Illinois is an example of CDC's state-based arthritis programs.

Illinois: Reaching Rural and Underserved Populations: Promoting Physical Activity Interventions for People with Arthritis

In Illinois, 2.1 million adults had doctor-diagnosed arthritis and an additional 940,000 reported chronic joint symptoms in 2001. In Illinois, the prevalence of arthritis in rural areas is 33 percent, higher than the prevalence in Chicago (24 percent) other Illinois urban areas (29 percent).

With CDC support, Illinois is increasing its efforts to reduce the burden of arthritis by increasing the availability of evidence-based arthritis physical activity programs in five counties, representing rural and underserved populations. In partnership with county health departments, the Arthritis Foundation's PACE (People with Arthritis Can Exercise), Aquatics and Arthritis Self-Help Course programs are being offered, reaching over 700 new participants. The coordinators responsible for these projects at the county level report that interest in and demand for the programs has exceeded expectations. In fact, coordinators are recruiting more course leaders and looking for additional venues to offer programs to meet this demand. Working through local health departments may be an efficient way to provide evidenced-based programs to people with arthritis in rural and underserved areas.

Implications and Impact

Arthritis-specific interventions have been proven to reduce the impact of arthritis or chronic joint symptoms by improving function and reducing pain and the need for physician visits. These interventions, however, are scarce in rural and underserved areas where people at risk of arthritis-related disability reside. This Illinois strategy to expand these community-based programs can serve as a model to help other States increase the availability of similar programs in rural and underserved areas.

We will continue to work with States, as many have limited resources—only enough to conduct modest demonstration projects. States will be challenged to ensure that self management education and physical activity programs for arthritis are available statewide.

Improve the Science Base

- CDC has provided long-term support to the *Johnston County (NC) Osteoarthritis Project*, a unique, population-based, longitudinal study of hip and knee osteoarthritis among 3200 rural white and black residents aged 45 and older. Hip and knee osteoarthritis are two of the most common, disabling, and expensive types of arthritis.
 - The Project has already shown a higher rate of hip and knee osteoarthritis among blacks than previously thought, the importance of overweight in the development of osteoarthritis among blacks, and the importance of pain in determining the functional limitations that occur.
 - Expected findings will better characterize the impact of osteoarthritis on previously understudied groups (e.g., blacks, rural residents) and suggest the high risk groups among them for targeted interventions.
 - Additional studies will find factors linked to the initial occurrence as well as subsequent progression of osteoarthritis, which will allow us to determine: (1) which biomarkers (e.g., blood tests, genes) can be used to make an earlier diagnosis and to suggest who needs more aggressive treatment, (2) how single and combinations of factors (e.g., joint injury, obesity, age, body composition, osteoarthritis in other joints) put a person at higher risk, and (3) how a person can modify these factors to reduce their impact.
- CDC co-sponsored "Stepping Away from OA: Prevention of Onset, Progression, and Disability of Osteoarthritis." This NIH-led effort addressed the preventive aspects of this most common type of arthritis.
- CDC co-sponsored a 2003 international conference summarizing the evidence for exercise and physical activity as underused interventions to prevent arthritis disability. This conference also made recommendations about what needs to be done next for biomedical and population-based research.

Identify and Evaluate Promising Interventions

Public health goals for arthritis include increasing the use of effective self-management strategies to minimize pain and optimize function among people with arthritis. Central to achieving this goal is identifying and evaluating promising interventions—those interventions that have demonstrated some potential to improve the quality of life for people with arthritis. We are working to develop sufficient scientific evidence so we can confidently tell Americans with arthritis 'if you participate in this activity, you can receive this benefit'.

- CDC is also funding the evaluation of several public health interventions designed to increase physical activity among people with arthritis.

The PACE (People with Arthritis CAN Exercise) program, developed and disseminated by the Arthritis Foundation specifically for people with arthritis, is currently being evaluated at the Universities of Missouri and North Carolina. This program teaches program participants exercises which can reduce their pain and improve their ability to move; pilot results are promising.

Active Living Every Day, a program developed by the Cooper Clinic, is a program that has been demonstrated to help people increase their physical activity by specifically attending to barriers that get in their way. Past evaluations have shown that participants have improved cardio-respiratory fitness and reduce blood pressure and body fat percentage. These evaluations have not addressed people with arthritis. The University of North Carolina is evaluating the Active Living Every Day program among people with arthritis.

Increasing Awareness—Reaching the Public

CDC and its partners are also reaching Americans with arthritis through mass media—specifically radio, newspapers, and displays at their local stores.

- CDC has developed a marketing campaign to promote physical activity among people with arthritis. The campaign was designed with an arthritis-specific message, to reflect a major motivator for people with arthritis. Audience research demonstrated that what people with arthritis are most seeking is pain relief, though most do not want to depend on medications for their pain relief. This research led to the development of the marketing campaign: *Physical Activity. The Arthritis Pain Reliever*. This campaign was quite successful in pilot testing: 50 percent reported hearing or seeing the message and 20 percent reported increasing their physical activity in response to something they heard or read. This campaign is currently being used by 35 of the 36 State health departments who receive arthritis funding from CDC.

Oregon: Using the Media to Reach People With Arthritis: Physical Activity. The Arthritis Pain Reliever

Public Health Problem

In Oregon, 567,000 adults had doctor-diagnosed arthritis and an additional 365,000 reported chronic joint symptoms in 2001.

Program Example

With CDC support, the Oregon Department of Human Services, Arthritis Program, pilot tested the CDC-developed health communications campaign, *Physical Activity. The Arthritis Pain Reliever*, in Bend, Oregon (Population 52,000). The campaign used a combination of radio, print and television media to reach the target population. Arthritis prevalence is estimated to be 39 percent in this area.

Implications and Impact

The campaign reached its target audience. In a post campaign survey of 300 adults with arthritis.

- 56 percent reported hearing a message about the health benefits of physical activity for arthritis;
- Of those who heard the message, 24 percent recalled the campaign theme, “Physical activity. The arthritis pain reliever.” 71 percent recalled “Physical activity is good for arthritis;”
- 14 percent of people in the campaign target group (ages 45 to 64, lower SES, white and African American) reported increasing their physical activity in response to something they read or heard.

The CDC-developed campaign performed well in the Oregon implementation in both reaching the target audience and producing significant changes in reported health behavior. Most CDC-funded State arthritis programs are planning to implement *Physical Activity. The Arthritis Pain Reliever*. The Oregon implementation experience serves as a model for other States.

Improve How We Measure the Burden of Arthritis

- Consistent with recommendations in the National Arthritis Action Plan, CDC has improved methods used to monitor the burden and cost of arthritis in general, and as described above has established its impact on mortality, hospitalization, ambulatory care visits, and disability. We plan to do the same for specific types of arthritis, such as osteoarthritis, rheumatoid arthritis, and systemic lupus

erythematosus, and for children as well, where arthritis impact is poorly understood. Standard data sources don't help much for rare diseases like systemic lupus erythematosus, so CDC is supporting the development of special registries in Michigan and Georgia to best determine the impact.

In conclusion, I would like to thank the committee for its leadership and commitment to the health of our Nation and the interest in people affected by arthritis. Great progress has been made in addressing arthritis, one of our most common chronic conditions. The Nation has a national plan, catalyzing activities in both the public and private sectors. State programs, almost unheard of just 6 years ago exist in 36 States. The pain and disability of arthritis can be improved. We need to continue our work to identify promising approaches, develop new approaches, and put this science into action—getting programs that work out to the people who need them.

I would be happy to answer any questions from the committee.

REFERENCES

- 1a. Arthritis Foundation, Association of State and Territorial Health Officials, CDC. National Arthritis Action Plan: A Public Health Strategy. Atlanta, Georgia: Arthritis Foundation, 1999.
- 1b. HP2010 Health Objectives for the Nation.
- 1c. Arthritis Foundation, *Primer on the Rheumatic Diseases*, 2001. 12th Edition, John H. Klippel, Editor. Arthritis Foundation; Atlanta, GA.
2. Bolen J, Helmick CG, Sacks J, Langmaid G. Prevalence of Self-Reported Arthritis or Chronic Joint Symptoms Among Adults—United States, 2001, *MMWR*, 2002; 51(42):948–50.
3. Hootman JM, Helmick CG, Langmaid G. Public Health and Aging: Projected Prevalence of Self-Reported Arthritis or Chronic Joint Symptoms Among Persons Aged ≥ 65 Years—United States, 2005–2030. *MMWR*, 2003; 52(21):489–91.
4. Sacks JJ, Helmick CG, Langmaid G. Deaths from Arthritis and Other Rheumatic Conditions, United States, 1979–1998. In Press: *J Rheumatol*, 2004.
5. Sacks JJ, Helmick CG, Langmaid G, Sniezek JE. Trends in Deaths From Systemic Lupus Erythematosus—United States, 1979–1998. *MMWR*, 2002; 51(17):371–4.
6. Centers for Disease Control and Prevention. Prevalence of Arthritis—United States, 1997. *MMWR*; 2001; 50(17):334–6.
7. Sokka, T. Work Disability in Early Rheumatoid Arthritis. *Clin Exp Rheumatol*, 2003; 21(5 suppl):S71–4.
8. Lethbridge-Cejku M, Helmick CG, Popovic JR. Hospitalizations for Arthritis and Other Rheumatic Conditions: Data From the 1997 National Hospital Discharge Survey. *Med Care*, 2003; 41(12):1367–73.
9. Hootman JM, Helmick CG, Schappert SM. Magnitude and Characteristics of Arthritis and Other Rheumatic Conditions on Ambulatory Medical Care Visits, United States, 1997. *Arthritis Care Res*, 2002; 47(6):571–81.
10. Murphy L, Cisternas M, Yelin E, et al. Update: Direct and Indirect Costs of Arthritis and Other Rheumatic Conditions—United States, 1997. *MMWR*, 2004; 53(18):388–9.
11. Mili FD, Helmick CG, Zack MM, Moriarty D. Health-Related Quality of Life Among Adults Reporting Arthritis: Behavioral Risk Factor Surveillance System, 15 States and Puerto Rico, 1996–1999. *Journal of Rheumatology* 2003; 30:160–6.
12. Mehrotra C, Naimi T, Seruda M, Bolen J, Pearson K. Arthritis, Body Mass Index, and Professional Advice to Lose Weight: Implications for Clinical Medicine and Public Health. In press: *Am J Prev Med*.
13. Hootman JM, Macera CA, Ham S, Helmick CG, Sniezek JE. Physical Activity Levels Among the General US Adult Population and in Adults With and Without Arthritis. *Arthritis and Rheumatism (Arthritis Care and Research)* 2003; 49(1):129–135.
- 13a. Fontaine K, Heo M, Bathon J. Are U.S. Adults With Arthritis Meeting Public Health Recommendation for Physical Activity? *Arthritis and Rheumatism* 2004; 50(2):624–28.
14. Wang G, Helmick CG, Macera A, Zhang P, Pratt M. Inactivity-Associated Medical Costs Among U.S. Adults With Arthritis. *Arthritis Care and Research* 2001; 45:439–445.
15. Rao JK, Callahan LF, Helmick CG. Characteristics of Persons With Self-Reported Arthritis and Other Rheumatic Conditions Who Do Not See a Doctor. *J Rheumatol* 1997; 24:169–73.

16. Bolen JC, Helmick CG, Sacks JJ, Langmaid G. Adults Who Have Never Seen a Health-Care Provider for Chronic Joint Symptoms—United States, 2001. *Morbidity and Mortality Weekly Report* 2003; 52:416–419.

17. Boutaugh ML. Arthritis Foundation Community-Based Physical Activity Programs: Effectiveness and Implementation Issues. *Arthritis & Rheumatism (Arthritis Care & Research)* 49(3):463–470, 2003.

18. Breedveld F, Kalden J. Appropriate and Effective Management of Rheumatoid Arthritis. *Ann Rheum Dis* 2004; 63:627–633.

19. Minor M. 2002 Exercise and Physical Activity Conference, St. Louis, Missouri: Exercise and Arthritis “We Know a Little Bit About a Lot of Things . . .” *Arthritis and Rheumatism (Arthritis Care and Research)* 2003; 49(1):1–2.

20. American College of Rheumatology/Association of Rheumatology Health Professionals. Proceedings from the International Conference on Health Promotion and Disability Prevention for Individuals and Populations With Rheumatic Disease: The Evidence for Exercise and Physical Activity. 2003. Atlanta, Georgia.

21. Lorig K, Mazonson P, Holman HR: Evidence Suggesting That Health Education for Self-Management in Patients With Chronic Arthritis Has Sustained Health Benefits While Reducing Health Care Costs. *Arthritis and Rheumatism*, 36(4):439–446, 1993.

22. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW, Bandura A, Gonzales VM, Laurent DD, Holman HR. Chronic Disease Self-Management Program—2-Year Health Status and Health Care Utilization Outcomes. *Medical Care* 39(11): 1217–1223, 2001.

23. ORC Macro. Market Research For The Arthritis Foundation. A Focus Group Study. May 2003.

24. Toal S. Assessment of Arthritis Program Capacity. Unpublished Report Prepared for the Arthritis Council, Chronic Disease Directors, March 2004.

25. Jordan JM, Renner JB, Luta G, Dragomir A, Fryer JG, Helmick CG, Hochberg MC. Hip Osteoarthritis (OA) Is Not Rare In African-Americans And Is Different Than In Caucasians. *Arthritis Rheum.* 1997; 40(9)suppl: S236 (#1232).

26. Jordan JM, Luta G, Renner JB, Dragomir A, Fryer JG, Helmick CG, Hochberg MC. African-Americans Face An Increased Risk of Bilateral Knee Osteoarthritis (OA) From Obesity. *Arthritis Rheum.* 1997; 40(9)suppl:S331 (#1796).

27. Jordan JM, Luta G, Renner JB, Linder GF, Dragomir A, Helmick CG, Fryer JG. Self-Reported Functional Status in Osteoarthritis of the Knee in a Rural, Southern Community: The Role of Sociodemographic Factors, Obesity, and Knee Pain. *Arthritis Care Res.* 1996; 9:273–278.

28. Jordan JM, Luta G, Renner JB, Dragomir A, Hochberg MC, Fryer JG. Knee Pain and Knee Osteoarthritis Severity in Self-Reported Task-Specific Disability: The Johnston County Osteoarthritis Project. *J Rheumatol.* 1997; 24:1344–1349.

29. Felson DT, Lawrence R, Dieppe PA, Hirsch R, Helmick CG, Jordan JM, et al. Osteoarthritis: New Insights. *Ann Intern Med* 2000; 133:635–646.

30. Dunn AL, Marcus BH, Kampert JB, et al. Comparison of Lifestyle and Structured Interventions to Increase Physical Activity and Cardiorespiratory Fitness: A Randomized Controlled Trial. *JAMA*, 1999; 281(4):321–34.

31. Geppert J. Physical Activity. The Arthritis Pain Reliever. Pilot Test Results—Unpublished Report. 2003.

Senator BOND. Dr. Serrate-Sztein.

STATEMENT OF SUSANA SERRATE-SZTEIN, M.D., CHIEF, RHEUMATIC DISEASES BRANCH, NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES, NATIONAL INSTITUTES OF HEALTH

Dr. SERRATE-SZTEIN. Thank you very much. I am pleased to testify before you today to highlight recent research advances and new NIH initiatives in the field of arthritis research. The NIAMS is the lead institute at the NIH for research on arthritis and related diseases, though 18 other agency components also support research in this area. While the public health burden of arthritis and related diseases is significant—at the personal, community, and societal levels—we have made great progress in understanding these diseases and how best to diagnose, treat, and prevent them. Indeed, as the number of Americans affected by arthritis increases with the

growth and aging of the population, the research community is faced with growing challenges as well. The NIH is fully committed to meeting these new challenges and to taking advantage of the new promising scientific opportunities in this area of research.

Arthritis and related rheumatic diseases are characterized by inflammation and loss of function in one or more of the connective or supporting structures of the body—bones, muscles, tendons, joints, and ligaments. There are over 100 forms of arthritis. Most of them can affect children and adults, and they are often more serious and more common in women and minorities. Some of the more common forms include osteoarthritis, rheumatoid arthritis, fibromyalgia, lupus, and gout.

Arthritis research supported by the NIH covers a broad spectrum of basic, translational, and clinical studies and includes funding for major research centers and research registries which serve as national resources. By way of example, in the pediatric arena, the NIAMS funds a Multidisciplinary Clinical Research Center at the Children's Hospital Medical Center in Cincinnati which focuses on diseases such as juvenile rheumatoid arthritis, juvenile fibromyalgia, and juvenile dermatomyositis. The Institute also supports a Core Center on pediatric rheumatic diseases and research registries on JRA and neonatal lupus. Centers and registries strengthen the overall foundation for rheumatology research across the country and provide training opportunities for scientists who are interested in working on these devastating diseases.

In recent years, a number of important research advances have been made as a result of NIH-supported research. Highlights of these advances include:

- A better understanding of the intricacies of the inflammatory mechanisms that lead to joint destruction in osteoarthritis and rheumatoid arthritis;

- The discovery of a gene and gene polymorphisms that underlie susceptibility to diseases such as rheumatoid arthritis, juvenile arthritis, and lupus;

- The identification of genetic signatures in some patients with lupus who develop such life-threatening complications as blood disease, central nervous system damage, and kidney failure;

- The identification of biological markers that can predict rapid progression of rheumatoid arthritis and allow physicians to make early diagnosis and institute early aggressive treatment;

- Insights on the role that anxiety plays in long-term outcomes in children with juvenile arthritis.

While this is by no means a comprehensive listing of critical advances, it paints a clear picture of the considerable progress that has been made through NIH investments in this area of research.

There are many exciting initiatives across the NIH in arthritis research that are building on our growing body of evidence and understanding about these diseases. I will cite three examples that illustrate the promise of such initiatives to improve public health.

The first one relates to osteoarthritis. Osteoarthritis is the most common form or type of arthritis, especially among older people. Currently, we have no treatments to halt the progression of joint destruction other than surgical joint replacement. Clinical trials for new therapies are long, difficult, and expensive. In an effort to

speed up the discovery of markers of early disease, the NIH has launched a public-private partnership known as the Osteoarthritis Initiative, a collaborative effort between several NIH components and the private sector that will establish risk factors for onset and progression of disease. We have also launched an Osteoarthritis Biomarker Network that comprises researchers that will identify and move laboratory findings to the clinical arena for early diagnosis of disease.

In lupus, we have launched a clinical trial to prevent the progression of atherosclerosis in children with lupus. Lupus is an inflammatory, autoimmune disease that can cause damage to various body tissues, including the skin, the heart, the lung, and the brain. Children who have lupus are at higher risk for cardiovascular disease due to the buildup of fat in blood vessels.

This clinical trial, called the APPLE trial, is being conducted by a network of pediatric rheumatology centers, also supported by the Childhood Arthritis and Rheumatology Research Alliance, or CARRA, a national network supported in part by the Arthritis Foundation. Ultimately, the scientists in this trial hope that the statin treatment will have preventive effects on the arterial fat buildup that occurs in these young patients, often leading them to stroke and myocardial infarction in their 20s.

Finally, I want to mention an intramural effort here at the clinical center at NIH, the NIH Pediatric Rheumatology Clinic. The clinic is a specialty-care medical facility dedicated to evaluating and treating children with pediatric rheumatic diseases who are enrolled in clinical trials.

In summary, the NIH is committed to supporting arthritis research across a broad spectrum, from basic and clinical studies to prevention and behavioral investigations. We are proud of the progress that we have made since the Institute was formed in 1986, and we are poised to take advantage of emerging opportunities in all areas of science for the benefit of affected patients.

Thank you for the opportunity to present this testimony. I will be happy to answer any questions.

[The prepared statement of Dr. Serrate-Sztein follows:]

PREPARED STATEMENT OF SUSANA SERRATE-SZTEIN, M.D.

Good morning Mr. Chairman and Members of the Subcommittee. I am Dr. Susana Serrate-Sztein, Chief of the Rheumatic Diseases Branch in the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health (NIH). The NIAMS is the lead Institute at the NIH for research on arthritis and related diseases, though 18 other agency components also support research in this area. I am pleased to have this opportunity to testify before you today to highlight recent research advances and new NIH initiatives in the field of arthritis research. While the public health burden of arthritis and related conditions is significant—at the personal, community, and societal levels—we have made notable progress in understanding these diseases and how best to diagnose, treat, and ultimately prevent them. Indeed, as the number of Americans affected by arthritis increases with the aging of the population, the research community is faced with growing challenges as well. The NIH is fully committed to meeting these new challenges, and to pursuing the many promising scientific opportunities in this area of research.

INTRODUCTION

Arthritis and related rheumatic diseases are characterized by inflammation and loss of function in one or more connecting or supporting structures of the body. These disorders especially affect the joints, tendons, ligaments, bones, and muscles.

Common symptoms include pain, swelling, and stiffness that can be debilitating. Some rheumatic diseases also involve the internal organs. There are over 100 forms of arthritis and related conditions, and many of them can affect both children and adults. Research has shown that a number of these disorders are autoimmune in nature, and affect women and minorities disproportionately. Some of the more common forms include osteoarthritis (OA), rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), scleroderma, and fibromyalgia.

RECENT ADVANCES

Arthritis research supported by the NIH covers a broad spectrum of basic, translational, and clinical studies, and includes funding for major research centers and research registries which serve as a national resource. By way of example, in the pediatric arena, the NIAMS funds a Multidisciplinary Clinical Research Center at the Children's Hospital Medical Center in Cincinnati which focuses on diseases such as juvenile rheumatoid arthritis (JRA), juvenile fibromyalgia, and juvenile dermatomyositis. The Institute also supports a Core Center on pediatric rheumatic diseases, and a research registry on JRA, at the Cincinnati Children's Hospital. At the Hospital for Joint Diseases in New York, the NIAMS is funding a research registry for neonatal lupus. Both the centers and the registries strengthen the overall foundation for rheumatology research across the country, and provide training opportunities for scientists who are interested in studying these often devastating diseases.

In recent years, a number of important advances have been made as a result of NIH-supported research. Highlights of these advances include:

- A better understanding of the genetics of RA, including the role of inflammation in cells lining the joints, and how these inflammatory processes contribute to joint destruction.
- The identification of biological markers that can predict rapid progression of RA, allowing physicians to develop treatment strategies based on the likely course of disease in affected patients.
- The discovery that a variation within the interleukin-6 (IL-6) gene increases susceptibility to systemic juvenile rheumatoid arthritis, the most severe type of this pediatric disease. Progress in uncovering such disease-associated genes may lead to clinically useful subgroupings for affected patients.
- New insights into the role that increased anxiety—rather than depressed mood—plays in heightening the fatigue and pain associated with juvenile arthritis. Researchers found that a comprehensive treatment approach that addresses pain and fatigue can optimize affected children's participation in school and social activities.
- A better understanding of the bone and cardiovascular changes experienced by young women with lupus. New findings indicate that women with lupus are at increased risk for both clinical osteoporosis and cardiovascular complications at a much younger age, suggesting that more aggressive treatments are needed for this population.
- The identification of a genetic "signature" in some patients with lupus who develop such life-threatening complications as blood disorders, central nervous system damage, and kidney failure.
- The discovery that scleroderma cells are resistant to factors that can normally regulate the production of collagen, a major protein component of the skin and connective tissue. The results suggest that, by targeting these factors, new therapeutics could be developed to restore a balanced collagen synthesis in scleroderma cells.
- The finding that the drug etanercept—one of the new "biologic" therapies that are designed to interfere with specific biological processes associated with rheumatic disease—alleviates the pain and stiffness associated with ankylosing spondylitis (spinal arthritis). This type of arthritis typically strikes adolescent and young adult males.

While this is by no means a comprehensive listing of critical advances, it paints a clear picture of the considerable progress that has been made through NIH's investments in this area of research.

NEW INITIATIVES

There are many exciting initiatives across the NIH in arthritis research that are building on our growing understanding of the underlying mechanisms of disease, as well as the cellular, genetic, and environmental factors involved. I will cite three examples that illustrate the promise of such initiatives to improve public health.

The Osteoarthritis Initiative

Osteoarthritis (OA) is a degenerative condition whose hallmarks are joint pain and limited movement resulting from progressive loss of cartilage. OA is the most common type of arthritis, especially among older people. Currently, there are no treatments, other than surgical joint replacement, that significantly change the course of this disease. Clinical trials for new therapies are long, difficult, and expensive.

In an effort to hasten the discovery of new biological markers for OA which can be used in clinical studies of potential treatments, the NIH launched a public-private partnership known as the Osteoarthritis Initiative (OAI). This collaboration—which includes several NIH components as well as three private sector partners—is supporting four clinical sites around the country, and a data coordinating center. These sites will recruit a total of 5,000 men and women age 45 and older and follow them for 5 years. Through the collection and analysis of biological specimens, images, and clinical data, the researchers leading the OAI hope to find markers that will, ultimately, enable doctors to identify individuals at risk for OA and people with OA at risk for disease progression.

In a related effort, the NIAMS is also supporting a new OA biomarkers network to bring together researchers to share clinical, biological, and human resources. Through this novel network, scientists will learn more about joint destruction by identifying and monitoring biomarkers in joint, bone, and synovial tissues. These efforts could provide the clues needed to better define the stages of OA on a more consistent and reliable basis.

The APPLE Trial

Systemic lupus erythematosus (SLE) is a chronic, inflammatory, autoimmune disease that can cause damage to various body tissues, including the joints, skin, kidneys, heart, lungs, blood vessels, and the brain. Studies have shown that women are much more likely to have the disease than men, and that it affects African Americans, Asians, and Native Americans more commonly than Caucasians. Children who have lupus are at higher risk for cardiovascular disease, due to the build-up of fat in the blood vessels.

To better understand this potentially life-threatening complication of lupus in pediatric patients, NIAMS is funding a study of statins—drugs used to lower “bad” cholesterol levels—to test their effects against fat buildup in the blood vessels of these children. This 5-year study, the Atherosclerosis Prevention in Pediatric Lupus Erythematosus (APPLE) trial, will involve 280 children diagnosed with SLE. Recruitment will be facilitated by the Childhood Arthritis and Rheumatology Research Alliance (CARRA), a national network designed to enhance pediatric rheumatology studies. Researchers will use a double-blind, placebo-controlled approach to randomize patients to receive either statins or a placebo for 36 months. Atherosclerosis will be measured at baseline and at 6-month intervals using ultrasound imaging. Ultimately, the scientists hope that the statin treatment will have preventive effects on the arterial fat buildup that occurs in these young patients.

The NIH Pediatric Rheumatology Clinic

NIH’s Pediatric Rheumatology Clinic, a component of our intramural research program, is a specialty-care medical facility dedicated to evaluating and treating children with pediatric rheumatic diseases who are enrolled in clinical trials. These trials may be studies of the natural history, signs, and symptoms of disease when standard treatment is given, or can include experimental treatment or diagnostic tests.

Current studies at the Pediatric Rheumatology Clinic include:

- An investigation of the most effective dosing regime of the drug infliximab, one of the new biologic agents, for children with juvenile rheumatoid arthritis. The trial will look at the safety and effectiveness of a stepwise dosing regime, rather than a fixed dose, for eligible children between the ages of 4 and 17 with active JRA who do not respond to standard therapy. The drug’s effects on bone and cartilage, and whether it can improve abnormal growth, metabolism, and hormones, will also be examined.
- A pilot trial to evaluate the safety and effectiveness of the drug anakinra, another novel biologic therapy, for treating patients with neonatal-onset multisystem inflammatory disease (NOMID). This disease can cause rash, joint deformities, brain inflammation, eye problems, and learning difficulties. Immune-suppressing medicines commonly used to treat NOMID do not completely control disease symptoms and, if used for a long time in high doses, can cause harmful side effects.

CONCLUSION

In summary, the NIH is committed to supporting arthritis research across a broad spectrum: from basic and animal studies, to clinical trials, to prevention and behavioral investigations. We are proud of the progress that has been made since the Institute was formed in 1986, and are poised to take advantage of emerging areas of science for the benefit of affected patients.

I would be happy to answer any questions you may have about arthritis research at the NIH.

Senator BOND. Thank you very much to you both. You have outlined comprehensive efforts, collaborative efforts. Pardon me for expressing a personal interest. What are the most promising things you are seeing? Where are you going? What are you looking at? What seems to be the most promising areas in which you are looking? Obviously, we have got to do a lot of communication. There are some things we know about that we need to communicate. But what would you say are the best hopes in this area?

Dr. Snizek, do you want to start?

Dr. SNIJEK. Yes, I can speak from sort of a public health perspective. We know that people with arthritis tend to be less active and heavier than people without arthritis. We know both of these things are bad for folks with arthritis. Physical activity is actually good for arthritis. It seems a bit counterintuitive, but it is. We are actually promoting physical activity and trying to get folks with arthritis to be more physically active, obviously achieving and maintaining a more normal weight.

We also know that people who learn how to manage their disease better do much better. They can learn how to better manage their disease. That is sort of the tack we are taking at this point in time, promoting physical and disease self-management strategies.

Senator BOND. Dr. Serrate-Sztein.

Dr. SERRATE-SZTEIN. In terms of research, I would mention three areas which I think could benefit from expedited efforts to accelerate research. The first one is on genetics. As I mentioned, at the NIH we support a number of projects on genetics. The identification of genetic factors for susceptibility and severity of disease that can also be used to identify patient subsets has the potential to allow physicians to make early diagnosis and treatment and identify those patients at high risk for bad disease that can tolerate the new treatments or more aggressive therapeutic approaches. So I think that is a very promising area of research. Technological advances really provide an opportunity for rapid progress.

The second area, and related, is the area of biomarkers of disease.

Senator BOND. I am sorry. Pardon?

Dr. SERRATE-SZTEIN. Biomarkers of disease onset and progression. We have a number of technological advances, from proteomics to molecular libraries, that would allow the subsetting of patients, the tailoring of individual treatments to particular patient subsets and so on. So I believe that the NIH and the research community are poised to make rapid progress in that area as well.

Finally, I think the area of chronic pain and the measurement of subjective patient-reported outcomes is another area in which progress can be made. The NIH is now involved in an initiative to develop automated instrumentation and procedures to record in a

reliable way patient-reported outcomes, such as pain and fatigue, which are so important in terms of quality of life for these patients.

Senator BOND. You are talking about public health outreach. You talked about Illinois. Are there things that we ought to add in legislation that would assist you in communicating the “Be active, lose weight” concept to those of our fellow arthritis sufferers? What can we do to help you get the word across?

Dr. SNIEZEK. Well, awareness is an important issue, and part of that is in the bill now. The devil is in the details. Getting people physically active, getting people at a normal weight, and getting these programs out is what we need to do. Those are some of the things that we need to do. We need to develop programs because we need more tools in the toolbox, so to speak. So those are some of the research challenges we will have. So awareness will be an important issue.

Senator BOND. You stated that 21 million Americans reported chronic joint symptoms. What does that really mean? And how can we define it so people understand it better?

Dr. SNIEZEK. The 21 million are people who have had chronic joint symptoms for more than 3 months and they have not received a diagnosis from a doctor. These people may have arthritis, they may not have arthritis. There are other things that could account for this. But these people should see their physician and figure out whether they do have arthritis or not so they can have appropriate management and learn how to do appropriate self-management.

Senator BOND. Dr. Serrate-Sztein, you mentioned fibromyalgia, which my mother-in-law suffers from. What is happening in that area?

Dr. SERRATE-SZTEIN. Well, the Institute has been involved in a number of activities in fibromyalgia. As you know, we have had two major initiatives over the last 10 years to try to promote basic and clinical research on fibromyalgia.

Last September, we conducted an assessment of the portfolio of grants at the NIH that relate to fibromyalgia research, and as a consequence, we produced a report that is published on our website that identifies areas of research that may benefit from further activity, including the need for agreement on clinical diagnostic criteria; the need for integrated studies of central nervous system mechanisms and peripheral mechanisms of pain; the need for natural history studies that identify the characteristics of disease in adolescents, young adults, and older adults.

We are also in the process of organizing another national meeting on fibromyalgia that will be in place or will be conducted later this year.

We have a number of studies on behavioral research looking at how to tailor treatments to patients with fibromyalgia according to certain characteristics related not only to their disease but also to their particular personalities and ability to cope with the disease.

So we are investing in a growing portfolio of research projects to cover all these areas of research on fibromyalgia.

Senator BOND. Thank you very much.

I will turn to Senator Mikulski.

Senator MIKULSKI. Thank you very much, Senator Bond.

I want to thank both of you for your outstanding work, so please don't misunderstand, but I am going to be a little bit aggressive here. It is more of an interest than an outcome.

I am really concerned that, for example, in my own State—that goes to this whole public awareness issue—that only 13 percent of the adults with arthritis in Maryland have utilized an arthritis education, self-help, or physical activity program. So my question, Dr. Sniezek, I am concerned that—two things. One, of course, we need more research; of course, we need more breakthroughs across all ages. There is no doubt about it. But we already know some things, and my belief is the only thing people know is go to your doctor and he is going to give you a pill.

My point is I don't think our awareness is working. Again, this is a no-fault conversation. I am going to ask you to respond, and I am going to also then take you to a physician's office and ask you what are you doing there.

Dorothy Hamill, one of our beloved ice skaters, is a Maryland resident, and she has arthritis, and we see her on TV actually advertising one of the pain management, agile management drugs. She also works out ice skating every single day at a workout center in Maryland.

Now, the drug ads seem to be more effective in telling you what to do than anything we do. That is number one. You know, I have got faith-based initiative, and these are all nice, but they have no traction. I really am beginning to think that our statewide efforts are of very limited utility. You could argue with me, and I invite you to argue with me.

The second thing is: Where do people go? They go see their doctor. What is it they want? They want two things: No. 1, the alleviation of pain, which is indeed severe; and, No. 2, anything that will increase their agility and their mobility, the ability to do—there are people who would cry their eyes out to do just what I just did right here.

So my questions are: No. 1, why are our State programs a flop? Are they a flop? And, No. 2, what are we doing in terms of getting into the physician's office? Because you get very little advice about weight, activity, and so on there.

Dr. SNIEZEK. Calling our State programs a flop seems a bit strong.

Senator MIKULSKI. Okay. But do you understand, 13 percent in Maryland—

Dr. SNIEZEK. I do understand and—

Senator MIKULSKI [CONTINUING]. That is why I said I am going to raise it in the spirit of great collegiality, but within a devil's advocate framework.

Dr. SNIEZEK [CONTINUING]. Yes, and I understand.

Senator BOND. That should be good that it is in the spirit of collegiality because what Senator Mikulski really means, it is much different.

[Laughter.]

Dr. SNIEZEK. Our State programs are fairly new. We have really only had money out to the States since about 2000 when activities began, and efforts at the State are limited.

Now, you talked about awareness of it. We do have our health communications campaign that has been implemented by some of our States. Now, the campaign, which has had limited implementation because it can only be done in limited areas of States, seems to be effective. The way I want to respond is we need to do more of this sort of thing where we can reach people. From our health communications campaign, 50 percent of the people who were in the target area seem to have heard the campaign; 20 percent got the message. This is very positive for a health communications campaign.

One of the things that we really need to learn to do is how to better reach people. You are absolutely right in that people don't know about the physical activity programs. We have done some market research. The Arthritis Foundation has done some market research recently. People don't know these programs are out there.

Senator MIKULSKI. What do they do when they go to a doctor's office? Are you really doing a massive public education for clinicians?

Dr. SНИЕZEK. We are not doing a massive public education for clinicians.

Senator MIKULSKI. Where do people get most of their information?

Dr. SНИЕZEK. People get most of their information—well, what we found in our market research for our health communications campaign is people get information when they stumble upon it.

The other thing we learned from the research we did for the health communications campaign, people aren't necessarily looking for a pill. This was surprising. However, physicians felt like their patients were looking for a pill. Physicians had very, very limited knowledge of other things.

Senator MIKULSKI. So then what are you doing about the physicians?

Dr. SНИЕZEK. We have only begun our efforts trying to think about how we are going to impact—

Senator MIKULSKI. Do you have a plan on doing this yet?

Dr. SНИЕZEK [CONTINUING]. We have started working with the health system. We have gone into Missouri and in Florida trying to change the system to provide better care for people with arthritis. What we actually did was we worked with teams of physicians treating people with arthritis and trying to get them to better assess function, pain, and support people in their self-management activities and then promote those activities. But we need to do more of this.

Senator MIKULSKI. Well, my time is up. I would like to urge two things. No. 1, there is a saying in social work—of which I am—you meet people where they are, not where you want them to be. Where people are in physicians' offices, or at least for an older group of people, often through Offices of Aging that do an incredible sense of outreach, and they are the ones that do the physical activity, the food, nutrition work. I would urge, No. 1, a real coordination with the Office on Aging if you are not doing it already. But I really would emphasize the need to really work with the physician community, because every doctor I know wants to, No. 1, help patients, alleviate suffering, and increase the quality of life of a

person. I think that is where a lot of what we need to do lies. I think the State programs are nice, but I believe the real State effort is not through health departments, though that is an important step. It is really through the Offices on Aging.

So I look forward to hearing what those plans are.

Senator BOND. Thank you very much, Senator Mikulski, and thank you for your clear-cut directions.

Now we are very pleased to be joined by the Senator from Washington, Senator Murray.

Senator MURRAY. Thank you, Mr. Chairman, and I echo the comments of Senator Mikulski as well, and her advocacy on behalf of this issue I really, really appreciate. I agree with her that this is kind of the silent epidemic out there. People who suffer from it suffer in silence a lot of times, just simply not going out. I think this kind of hearing really helps make the awareness, and I really appreciate you, Mr. Chairman, bringing this up.

The costs are staggering for arthritis. I have heard as high as \$51 billion. But there is also an economic cost associated with loss productivity, even younger women and men who get arthritis early and can't work, contribute to their families, and the costs to families are overwhelming. So I think it is really important that we start putting more emphasis on this at all levels. I know Senators Kennedy and Bond have introduced a bill on arthritis prevention, control, and cure, and I commend you for that. There is a lot in that that I have supported and have pushed for.

I am worried about the funding on it. Putting it out there is nice, but we need to make sure that CDC and NIH have the resources to carry out the parts of it.

I think also we should be aware that there is a lot of new, exciting treatments for arthritis. Unfortunately, a lot of our Medicare rules prohibit people from using them, and I am specifically talking about some of the self-injectables like Enbrel that are out there, and Medicare covers them if you go to your doctor's office. It does not cover you if it is a self-injectable and you do it at home. We all know people with arthritis have trouble getting out of their home. So requiring them to go to the doctor in order to be reimbursed is really the wrong policy. I have been working on that for some time and hope to continue to do that because I think Medicare rules need to be written so that it helps patients, not help the reimbursement procedures.

Let me just ask quickly, I think, Dr. Serrate-Sztein, you mentioned that women are impacted more than men, and I wanted to particularly ask you about gender equity in clinical trials. Are we making sure that there are enough reviews to make sure that women are a part of these clinical trials so that the research does not go in the wrong direction and not take into account the number of women who are impacted by this disease?

Dr. SERRATE-SZTEIN. Absolutely. We are committed not only to having women but also minorities adequately represented in clinical trials and all clinical studies supported by the NIH. Just as a way of example, for our atherosclerosis prevention trial in children with lupus, we monitor those numbers on a monthly basis and are in contact with investigators and the nurse clinical coordinators in each of the sites on a monthly basis to make sure that they are re-

cruiting and attracting patients that represent the entire spectrum affected by this disease. This happens for all of the clinical trials that we are supporting.

Senator MURRAY. So do you monitor that and make sure that there is gender equity?

Dr. SERRATE-SZTEIN. We monitor recruitment and minority inclusion in the clinical trials supported by NIAMS on a monthly basis, yes.

Senator MURRAY. Okay. Very good. Let's make sure—

Dr. SERRATE-SZTEIN. I should say also that investigators are committed to having representation of women and minorities.

Senator MURRAY [CONTINUING]. I just think it is important that all of us continue to remind each other that that is a critical part of research and trials.

Dr. SERRATE-SZTEIN. Absolutely.

Senator MURRAY. I was curious whether there is any research going on in better early diagnosis of arthritis, rheumatoid arthritis.

Dr. SERRATE-SZTEIN. Yes. We support a number of projects where investigators are looking at molecules that may help, if present, identify patients who are at risk for more severe disease or for rapidly progressing disease. We have a number of projects, including one that I will mention by name, the Autoimmune Biomarker Consortium, which is funded—two universities participate: North Shore University Hospital in New York and the University of Minnesota. They are working with state-of-the-art new technology to identify patients who are at risk for either more severe disease or rapidly progressing disease, as well as to identify those who do not respond to some of the new biological treatments such as the ones that you mentioned.

Senator MURRAY. Dr. Sniezek, how many States currently have Arthritis Action Plans?

Dr. SNIEZEK. Almost all of them do.

Senator MURRAY. Almost all of them?

Dr. SNIEZEK. Yes.

Senator MURRAY. Are they all implementing them?

Dr. SNIEZEK. I am sorry. Let me rephrase that. Of those funded.

Senator MURRAY. Okay. How many were funded?

Dr. SNIEZEK. Thirty-six.

Senator MURRAY. All of them have actions plans or almost all of them do. What additional funding does CDC need to make sure that all 50 States do?

Dr. SNIEZEK. That is a difficult question to answer. Right now Congress gives us \$14.8 million for arthritis, and we have made some progress with that \$14.8 million. But we will be glad to get an answer back to you.

Senator MURRAY. Okay. I would appreciate knowing that because I think it is important. Arthritis does not limit itself to a few States.

One other question for you. How does CDC include pediatric cases in the action plans?

Dr. SNIEZEK. Pediatric arthritis does appear in the State action plans. As you know, it is a very rare condition, and trying to reach people through public health efforts for very rare conditions is dif-

ficult. But it is represented. We do not have any specific activities at this point in time.

Senator MURRAY. Okay.

Dr. SNIEZEK. Let me just add, one of the things we need to do is to better define the size of this problem and who is it and where.

Senator MURRAY. I am surprised you said it was a rare disorder. It seems to me I know a lot of people who have—

Dr. SNIEZEK. “Rare” is a relative term; 300,000 may not be rare, but compared to 21 million, yes.

Senator MURRAY [CONTINUING]. Are there some States with higher populations of pediatric—

Dr. SNIEZEK. We do not know the answer to that—arthritis or pediatric arthritis?

Senator MURRAY. Pediatric.

Dr. SNIEZEK. We do not, I do not know the answer to that.

Senator MURRAY. Arthritis in general, you do not know?

Dr. SNIEZEK. Well, States that tend to have older populations will have more people with arthritis. Obviously, larger States will have more people with arthritis.

Senator MURRAY. Okay. Thank you very much, Mr. Chairman.

Senator BOND. Thank you very much, Senator Murray.

I just want to know—proudly, we have more than doubled the funding on NIH. How much of that is going to arthritis, rheumatology and, specifically, how much of that doubling has gone to pediatric arthritis?

Dr. SERRATE-SZTEIN. I will have to provide those numbers for the record.

Senator BOND. I would appreciate it. Thank you very much.

Do you have any further questions, Senator Mikulski, Senator Murray?

Senator MIKULSKI. No.

Senator MURRAY. No.

Senator BOND. Well, thank you very much. We appreciate it, and I assure you that we are going to continue to work with you, and we will have lots more questions. We welcome your suggestions on how we can improve the bill and other steps we are taking, and obviously, the same request goes to the following panel and our very interested guests in addition to the witnesses.

Senator BOND. I would now like to call up the second panel, and we will have their full biographies included in the record. It gives me great pleasure to call on a Missourian, a neighbor, and good friends, and people who have a lot to say on this subject.

Our first witness is KaLea Kunkel, a sophomore at GW, who grew up in Oregon, Missouri, in the northwest part of our State. At age 19, KaLea has had many years of experience overcoming the challenges of living with a chronic disease. At age 4, she was diagnosed with juvenile arthritis, diffuse scleroderma—I will let her explain it—and she began her advocacy work in 1998 and continues to be a patient advocate. I first met KaLea and her family in 1998 when I spoke at the Arthritis Foundation “Kids Gets Arthritis, Too” rally in the Capitol.

Our second witness is Mr. Virg Jones, just across the border in Kansas City, KS, first diagnosed with rheumatoid arthritis 49 years ago at age 13. He has a remarkable story. He will share it

with us. He has been an active volunteer with the Arthritis Foundation, currently sits on the board of directors, is a past chairman, has a degree in accounting and economics from Emporia State, and went to work for the Federal Reserve Bank as an officer in the Research Division until he retired in 1994.

Next we will hear from Dr. Deborah Rothman, Director of Pediatrics and Rheumatology at Shriners Hospital for Children in Springfield, MA. She is a board-certified pediatric rheumatologist and treats children with rheumatoid arthritis, lupus, and dermatomyositis. She focuses on the treatment of these diseases.

Our final witness is Dr. John Klippel, president and CEO of the Arthritis Foundation. He has more than 30 years of experience in rheumatology and medical research. He joined the foundation in 1999 as medical director. Before that, he had served as clinical director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases at the National Institutes of Health.

Welcome to all of you. KaLea, if you would begin, please.

STATEMENT OF KALEA KUNKEL, PATIENT, OREGON, MO

Ms. KUNKEL. Thank you, Chairman Bond and Ranking Member Mikulski, and also the Members of the Subcommittee, for hosting today's hearing and for giving me an opportunity to testify on this important topic. As you know, my name is KaLea Kunkel, and I am 19 years old and a sophomore at—

Senator BOND. Would you pull that microphone a little close to you? Thank you.

Ms. KUNKEL [CONTINUING]. Is that better?

Senator BOND. That will help.

Ms. KUNKEL. I am a sophomore at George Washington University. I grew up in Oregon, MO, a rural town of 900 people. I am speaking to this committee today as one of the 70 million Americans who live their life with the daily challenges of arthritis and rheumatic disease.

I was diagnosed with arthritis at age 4. This makes me one of about 300,000 children diagnosed with childhood rheumatic disease in the United States. I say "about" because the Federal Government has not yet undertaken a national prevalence study that tells us exactly how many children in the United States are affected by the over 100 forms of arthritis and related diseases. This legislation that we are discussing today would authorize the Centers for Disease Control and Prevention to undertake this important study.

My journey with arthritis began when my older sister, Kara, was diagnosed with a form of juvenile rheumatoid arthritis when she was 6 years old. My brother, sister, and I always accompanied Kara to her visits to the pediatric rheumatologist, 2 hours away at the University of Kansas Medical Center. This was the only hospital remotely near us that had a pediatric rheumatologist.

Two years after Kara was diagnosed, I began to experience strange changes in the color and temperature of my fingers and unusual changes in my skin. Following a battery of tests, I was diagnosed with an undifferentiated form of juvenile arthritis at the age of 4. However, it was another 3 years before we had the exact diagnosis of systemic scleroderma, a life-threatening autoimmune disease. Unlike JRA, which predominantly affects the joints and eyes

in children, scleroderma is a disease of fibrosis or hardening of the skin and internal organs, and for me, particular the esophagus, intestinal tract, thyroid, and lungs. It is very rare in children. Some people have this disease for years before they get an accurate diagnosis because, like many other forms of arthritis, scleroderma can be an invisible disease. The fact that I was able to have aggressive treatment very early in my disease has given me an improved prognosis.

I was fortunate that I had a pediatric rheumatologist nearby to treat my scleroderma. Children in many other States, such as South Carolina, Alabama, Wyoming, and New Hampshire, are not so fortunate. They do not have a pediatric rheumatologist in their State to provide them with the care that I received. The legislation before you today seeks to help families by establishing a limited loan repayment program for medical students who decide to pursue a career in pediatric rheumatology. This legislation also provides grants for those who conduct or promote the coordination of research, training, and studies related to the prevention of arthritis and other rheumatic diseases. Currently, less than half of the children who need treatment are receiving treatment by a pediatric rheumatologist. This program could mean the difference between life and death for children with juvenile arthritis and rheumatic disease.

As I look back on my childhood, I cannot remember a time when I did not deal with the daily battles of scleroderma. In the early stages of my disease, I had severe skin reactions and breathing difficulties, for example, when I touched certain substances like soybeans, since I grew up on a farm. When our second grade class carved pumpkins, I had to wear rubber gloves to protect my skin, but I still had a reaction. I had to leave class frequently to take pills and breathing treatments, never failing to draw attention toward my disease. At sleepovers with my friends, I had to stop to take a breathing treatment for 15 minutes while my friends stared at the machine producing a fog from the medication that opened my airways and helped alleviate daily breathing complications. I spent my recess time during the winter months watching my classmates play in the snow while I sat in the classroom and colored pictures; I was unable to explain why I could not join them outside, and I was always separated from kids my age. Adults were constantly reminding me to be careful, and I was not able to understand at the time the reasoning behind everyone's fears. I just wanted to be a normal kid like my friends, but every adult seemed terrified for me to do anything.

During my early school years, my skin would become severely dry and tight. It would cause cracks, then bleeding. There were days when I had blood dripping from my hands and legs and feet. Every motion shot pain through my body and my skin would burn. Nothing would bring any type of relief. My skin scarred because it split open so frequently. I found myself hiding my hands and my legs from my friends. I even found myself making up excuses about why my skin looked the way it did and why it was rough and dry. I was embarrassed to tell my friends any details about my scleroderma. Even though I realized I had scleroderma, the disease was just a name to me. The symptoms were just a bad dream. I

had always had health problems; they had simply become part of my daily life. Pain was normal for me, and I began to become immune to it. I got to a point long ago where I stopped wondering what normal was because normal had never been a concept that I was familiar with. I never understood what a normal pain level was or that my scleroderma could handicap me or even kill me one day.

When I was in the sixth grade, I remember watching the movie "For Hope." This movie is about television actor Bob Saget's sister and her struggle to cope with scleroderma. After the movie, I remember breaking down and bawling, which is something I would never do. I cried until my mother came into my room and found me. She did not want me to become alarmed, so she told me that the type of scleroderma the lady in the movie had was not the form I had, that I was not going to die like the lady in the movie. She said that my organs were not going to scar and stop functioning one day. I was not going to die like the woman in the movie did, in intense pain and unable to eat or even breathe. That day, she lied to protect me from the truth. Now I know that I do have the same form of scleroderma, and I dread the day that my medications stop controlling and slowing my disease activity.

Following a serious flare-up of my disease in sixth grade, I have come to expect difficult times and increased internal damage from my scleroderma. Nearly 8 years ago marked the beginning of my trials with severe acid reflux and a lack of intestinal mobility. Many days I opted not to eat because the reflux was so severe it would aspirate into my lungs. It burned, and on top of the pain, I could barely breathe because of the burning. My digestive problems mounted during my junior year in high school. I found myself in so much pain that I was gritting my teeth and taking chronic pain medications several times a day just to make it through the daylight hours.

My joints began to hurt so much that I could hardly walk or move. I was trying to play volleyball and cheer along with my friends, but I could not move my hips or even walk up a few stairs. I stopped eating because my reflux was too painful and the fatigue was so severe that I was doing nothing besides sleeping, but sleeping was even difficult because of the pain.

Some days I had to leave school and return home for a few hours to try to hide the pain from my teachers and classmates. My treatment took 5 months, countless invasive tests, and three new medical specialists to stabilize the condition. Before this flare-up, I always tried to block out the pain, thinking it would pass, but now I can no longer do that. My scleroderma was slowly fossilizing my body and scarring my internal organs. I could not fight the shots, CAT scans, regular blood tests, and countless doctors' appointments.

I began my freshman year at the George Washington University last fall, and I did well for the first several months of this semester. However, about the middle of October, my scleroderma became more intense than ever before due to reflux. I could not swallow or keep food down. My esophagus was not pushing food down into my stomach, my stomach was not breaking down what I ate, and my intestines were not absorbing and moving food through my system

fast enough. Not only was my entire digestive system in constant cramping pain, but my hips, knees, and shoulders became stiff and popped with each movement. By the end of October, I could not stand without getting dizzy, and all I could do was sleep. It became hard for me to keep any food in my stomach, and soon blood was coming up with what I ate. This wasn't surprising, however, because I threw up everything. I missed classes because I would get so dizzy that I almost blacked out on several occasions. I felt helpless knowing that this flare-up would send me back to another trip of trial and error at the doctor's office in an attempt to stop my disease's activity. Hours in the doctor's office are difficult, but as a young adult, hiding shots, countless medications, and a disease that limits daily functions like holding on to your college ID is far more painful.

Now, nearly 5 months later, I take 23 pills a day, a shot once a week, and I have five specialists, all of whom require regular appointments and specialized tests to monitor my scleroderma at least every 3 months. Blood and urine tests follow each appointment, and endoscopies with biopsies, lung function tests, and CAT scans remain among my annual medical examinations and tests. I have come to expect at least one flare-up a year, and each year I grow more nervous and worried as I watch my disease change my body. As I look back over the last 19 years, I do not remember the physical pain. I remember the ways I have tried to hide the pain and my disease from everyone, fighting the fact that it exists. I think of the progression of my scleroderma and wonder how long it will remain stable. But despite all the complications I deal with daily, I realize I am one of the lucky ones because I am still alive. I can still walk even if it is painful. I am still able to partially disguise my scleroderma while fighting what before has always been an inevitable outcome. I have grown to appreciate my doctors. If there is one thing I realize today, it is how lucky I am to have a family with health insurance and that is able to afford the hundreds of dollars a month it takes for my medications that are needed to stabilize my disease. I appreciate the fact that my parents saw the necessity in finding a pediatric rheumatologist, and I know that we are still among the few who have access to pediatric rheumatologists. I would not be alive today without the medical attention of a pediatric rheumatologist who aggressively treated my disease.

Most people do not think of arthritis as a fatal disease. But the fact remains that some forms of arthritis do result in death. My disease has always been closely monitored and treated, but without a pediatric rheumatologist and funding for research, people like myself who suffer from scleroderma and other forms of rheumatic disease will never be able to live a normal life.

I close by thanking Senators Bond and Kennedy for introducing the Arthritis Prevention, Control, and Cure Act. This legislation provides hope to me and the thousands of kids living with this terrible disease.

It is the hope that all children will have access to the special care they need and deserve.

It is the hope for a better understanding of what causes juvenile arthritis.

It is the hope that we will someday find a cure.

Thank you.

Senator BOND. Thank you, KaLea, for very compelling testimony, and we commend you for your bravery, and we thank you.

Mr. Jones.

STATEMENT OF VIRG JONES, PATIENT, KANSAS CITY, KA

Mr. JONES. Yes, thank you, Chairman Bond and Ranking Member Mikulski, for giving me the opportunity to come and tell my story this morning. I am going to be encouraging you to pass legislation that is going to give hope to millions of individuals that have arthritis, and particularly the 300,000 children. I think if I am asking you to provide hope, maybe the best thing I can do is to share with you what it is like when there is complete hopelessness for the individuals, and that would be my story.

Forty-nine years ago, I was 13 years old. I was an active athlete, and I had just started playing basketball after football season, and my left wrist became swollen and inflamed. The coach sent me to the doctor, and the doctor assumed that I had suffered some kind of injury playing basketball. So he put my left wrist in a splint that I could take off if I wanted to play. Being an active 13-year-old, I just took the splint off when I played and practiced, then put it back on.

Three weeks later, my right knee started to swell up and become inflamed, and the doctor said, "You really need to quit pushing yourself so hard. This is another athletic injury." So he encased my leg in a cast from my ankle up to my hip and said I needed to give it rest.

I stayed that way for 5 weeks, when all of a sudden all the rest of my joints started to get inflamed and swollen, and it became obvious that the diagnosis wasn't correct. When they took the cast off, my right leg was stiff; it was completely atrophied, all the muscles. They sent me to KU Med Center where the doctors diagnosed me with juvenile rheumatoid arthritis. I can remember sitting down with my parents and the doctors and them telling me I had juvenile arthritis, and my dad, being a little crusty, said, "You mean this kid has rheumatism." The doctor said, "Well, it is something like that." He says, "The only thing we can do for your son is to give him large doses of steroids and up to 24 aspirins a day, depending on how many it would take to make his ears start ringing, and send him home and tell him to just be as active as possible so his joints will not get stiff." They said, "You need to come back every 6 weeks, and we will check what the effect of the steroids are."

So I went home, and over the next 3 years, my condition deteriorated rather rapidly. It had a big impact on my family. My mom had to get up every 2 hours during the night to lift the sheets off of me because it was so painful, I couldn't even turn over in bed. She would even have extra sheets she would keep rolled up next to her so she could give me a warm sheet to help me go back to sleep. She would get up at 5 o'clock every morning, give me large doses of steroids and six aspirin so I could get up and go to school at 7 o'clock.

School was difficult, and by the time noon rolled around, I was hurting so bad and was tired that I couldn't climb up the steps in a building that was not disabled-accessible, three floors. My friends would help carry me up the steps to classes. After school, I would come home and just crash on the couch, and my mom would put hot towels on my feet and on my ankles and my knees, and I would sit there and eat my dinner on the couch and try to do my homework.

At the beginning of my junior year, I had a severe reaction to the steroids. The doctors didn't seem to know what to do. Some friends told my parents about a hospital in Hot Springs, AR, that specialized in the treatment of arthritis, and they took me to that hospital. That was a rather enlightening experience. At that time I got to meet 13 or 14 other children that had arthritis, and teenagers, and my parents got a chance for the first time to talk to other parents of children with arthritis. But even at that hospital, even though we took extensive therapy in hot water, there were no drugs available at that time to slow the progression of the disease.

Three weeks after I entered the hospital, I was in a wheelchair and I stayed there for 5 years, and my legs were pronated to 90 degrees. I couldn't stand up. My left wrist, the one they had put the splint on, was also pronated to 90 degrees, and I couldn't use my left hand at all. No matter what type of therapy—they tried some drugs, and as Senator Mikulski mentioned, gold. It looked pretty, but it didn't do any good for me. I tried that. I tried some Plaquenil, a malaria drug, but nothing worked. But it wasn't any different for me than it was the other children. All the children that were there were facing the same hopeless situation that I was facing. There was nothing to really help stop the disease.

After 5 years, the doctors told me that I could just go home and learn to live in a wheelchair for the rest of my life and do the best that I could, or else I could let a doctor in Hot Springs try some experimental surgery to reconstruct my knees. Since I had tried everything else, I thought, well, I couldn't lose anything. So I let him try the surgery, but it didn't work because, being in a wheelchair for 5 years, my bones had completely calcified in my knees and they could not do reconstructive surgery. Of course, there were no artificial joints available back then. So the doctor fused both of my knees to give me a chance to stand up again. That was experimental, too, because my hips were completely dysfunctional. My ankles are almost fused. I didn't have any strength in my arms. It was just an attempt to see if I could stand up.

Well, after a year of taking more extensive therapy to strengthen my muscles, I was able to walk out of the hospital on crutches, virtually like I am now, with two fused knees, two fused ankles, an elbow that was fused because of the arthritis, a wrist that was surgically fused. The hands they couldn't do anything with. Extreme pain all the time and very limited motion. I walked out of the hospital to face life. The thing I really learned in the hospital was that I was going to be fighting a war for the rest of my life with this disease. It was going to be relentless. I also learned that I better have a good sense of humor and not be too proud when it came to asking for help because I was going to need plenty of it.

When I entered college at Emporia State University in September of 1965, I had to hire somebody to help me put on my shoes and socks every morning and take them off every night, somebody to button my shirts for me if I wore a shirt with buttons because I can't button a shirt. I had to hire kids to help carry my books to class and back again at night. When the weather was really nasty, some of the football players, if the snow got too deep, they just carried me up to class on their shoulders.

That is the way I made it through school. I graduated in 1968 with a major in accounting and economics and started to work for the Federal Reserve Bank in Kansas City, got married 6 months later to my wife, Harriet.

For a few years, everything went really well. My wife would help me with all the things I needed help with every single day, until the time I was promoted to the official staff and I started to have to travel extensively throughout the Federal Reserve System with my job responsibilities. You can imagine what it must have been like that first day when my wife took me to the airport, kicked me out with my suitcase, and said, "Good luck." I was coming to Washington, D.C., by the way, to the Board of Governors. When I got here, I had to on my own figure out, you know, figure out some way to have somebody help me with my shoes and socks in the morning and at night, tie my necktie—of course, we always had to wear ties back then. It wasn't informal. Tie my necktie, button the collar on my shirt. Even at times when these hotels had showers with sliding glass doors, I might even have to ask somebody to help me get into the shower. That is what it was like for the 12 or 14 years I was on the official staff.

I got pretty creative in hotels where they didn't have bellmen. I got help from maintenance men, from the housekeepers, even from the hotel management. It didn't make any difference. Some guy was cutting the grass one time. I just said, you know, "Come give me a hand." Everybody was willing to help. But I got it done. I can't carry an umbrella. When I would get out of the car and it was raining, I would have to either ask the cabby to hold the paper over my head until I got to the building or just wave at somebody on the street to bring me an umbrella, to lend me their umbrella.

Climbing steps, and coming into your wonderful building this morning, I am glad I had my wife with me, or else I would have had to ask somebody to help me get up those steps.

That is the way it was for that time. A real challenge, but I think that the lessons I learned about arthritis helped me get through this.

My wife had asked me not to put anything in the testimony about our relationship and the adjustments she had to make in our married life, but I can tell you they were great. I married an angel, and she says she gets as much from me as she gives to me, but that is not true. Not only is she a housewife, she is a plumber, she is an electrician, she changes the oil in the tractor. She does all those things. She even gave up her teaching career early in our marriage because, for her, housekeeping was a full-time job.

My children, we had to adopt our two children because all the steroids prevented us from having children of our own. Raising children was another big challenge, where the sense of humor came

in very well, because when I tried to teach my kids to count, can you tell how many fingers I have up? Or my wife, when I ask her to get something and I point, can you tell which direction I am pointing? That is the type of thing that you live with every single day.

The Arthritis Foundation over the last 22 years has given me a platform that gives me frequent opportunities to go out and talk to parents and children with arthritis. In those presentations and the time I have to talk with them, I have always told them about the war they are going to be fighting for their whole life. I have told them about the opportunities that are available for them to get help. I tell them about the tools that they need to have to fight this disease.

But, surprisingly, what I see is not much different than what I faced 49 years ago. True, we have medications that can slow down some of the deformities that the kids are having if they get treatment early enough and it is aggressive enough. But the parents tell me that these medications don't always work on their children. These medications are developed of adults, and their children either can't tolerate it or they just don't work. They also tell me about how far they have to travel, 200 or 300 miles, to see a pediatric rheumatologist. They tell me how their disease wasn't diagnosed in time. All of these things show up, and the kids need help.

In closing, I would simply like to say, you know, thousands of people have helped me get where I am today. I am very grateful for that. But the kids today need help, and I don't want these kids to have to get the kind of help I got. I don't want them to have to look for help to button their shirts, to put on their shoes and socks, to tie their ties, to have people carry them upstairs, carry them through snow. That isn't the type of help they need. They need the type of help that this legislation can provide where they know they can get access to good doctors, the brightest researchers in the country can seek out ways to develop medicines for children. They can do research to hopefully find some way to cure this disease. Of course, I would like them to be able to someday prevent it.

It is my dream that someday before I die, I can stand up and talk about arthritis, juvenile arthritis, like people talk about polio and smallpox, and say, "This is what it used to be like when kids got arthritis." I hope that you will share that dream with me. I hope that you will use your pen and your vote and try to convince your colleagues to cosponsor this bill and get it into action because that is where the help is going to come from.

Thank you so much.

Senator BOND. Thank you very much, Mr. Jones. A very difficult but inspiring story.

[The prepared statement of Mr. Jones follows:]

PREPARED STATEMENT OF VIRG JONES

Thank you Chairman Bond, Ranking Member Mikulski, and all of the Members of the Subcommittee for hosting today's hearing and offering me the opportunity to share my story.

I was diagnosed with rheumatoid arthritis 49 years ago. At the age of 13, I was initially diagnosed with stress injuries from sports in which I was competing. This misdiagnosis resulted in the doctor putting my right leg in a cast and a splint on

my left wrist. After about 5 weeks, when all the rest of my joints began to swell and become painful, the doctors at Kansas University diagnosed my condition as juvenile arthritis. The doctors counseled me and my parents that the only treatment available would be large doses of steroids and up to 24 aspirins a day, depending on how many it would take to make my ears start ringing.

Additionally, they told us it was very important to “keep going” to maintain as much range of motion in my joints as possible. No regular exercise routines were discussed or prescribed and I was told to return to the doctor every 6 weeks to monitor the effects of the steroids. Over the next 3 years, my condition deteriorated steadily. My mom would have to get up every 2 hours during the night to help me turn over in bed because the weight of lifting the sheet was too painful. She even kept extra sheets rolled up next to her in bed because she knew the warm sheets would help me fall back to sleep easier. At 5 o'clock in the morning, she would give me the steroids and 6 aspirins I could get out of bed by 7 o'clock.

Staying in school was difficult. I was completely worn out by noon and the pain prevented me from climbing the steps in the three-story building. I thank god for strong friends who helped carry me up the flights when it was apparent I couldn't take another step. After school, I would crash on the couch and put hot towels on my hands and knees to relax and ease the pain.

It was very difficult for me to see the anguish on my parents' faces when the doctors told them there was absolutely nothing more they could do to slow or prevent the crippling effects of this disease. I had to drop out of school at the beginning of my junior year because of a severe reaction to the steroids. At that time, I was admitted to a hospital in Hot Springs, Arkansas, which specialized in the treatment of arthritis. But even there, there were no new drugs or other therapies to help my condition. My situation was by no means unique. Virtually everyone at the hospital, including numerous other children and teenagers, was facing the same challenges without any hope.

Three weeks after going to the hospital, I was confined to a wheelchair for the next 5 years. I only left the hospital for home a few weeks every summer. I suppose they kept me at the hospital for such a long time because I was so willing to try anything to improve my condition. After 5 years, they told me that I should go home and get use to being in a wheelchair for the rest of my life, or I might want to consider some experimental surgery to reconstruct my knees. I agreed to surgery, but it was not successful and the surgeon had to fuse my knees. That process entailed being flat on my back nearly 4 months with my legs in casts and traction.

I remained in the hospital for another year taking extensive therapy to strengthen muscles in my legs and back. In the fall of 1965, I started my first semester at Emporia State University. Over the next 3 years, I faced many new challenges as I dealt with the effects of having two fused knees; a fused left wrist and elbow, very limited use of my hands, and of course constant pain and limited range of motion in the rest of my joints. I had to hire a roommate to help me with my shoes and socks every morning and night, carry my books to class, and provide general assistance in getting around campus in inclement weather.

After graduating in July 1968, with a double major in economics and accounting, I started working in the Research Division at the Federal Reserve Bank of Kansas City. When I was promoted to the official staff, my job duties required me to travel extensively throughout the Federal Reserve System. On every trip, I had to seek assistance to carry my luggage and briefcase, help with putting on and taking off my shoes and socks, buttoning my shirt buttons, and tying my neckties. In those instances that I stayed at facilities that did not have bellmen, I became very creative in getting assistance from housekeepers, maintenance men, and even hotel management. Complete strangers were also willing to help me climb stairs, use their umbrella to get from the cab to a building when it was raining, open heavy doors, carry trays in cafeterias, and pick up anything I dropped on the floor.

I wish my experience with juvenile arthritis were unique; however,

Almost 50 years after I first experienced the pain of juvenile rheumatoid arthritis, there are still children today who are living with the terrible pain and disability associated with this disease. Unfortunately, many children continue to be misdiagnosed. Or, they are not being seen by a physician who is knowledgeable and/or comfortable using the newest therapies to aggressively and properly treat the disease.

There are less than 200 practicing pediatric rheumatologists in this country. In many States, there are none. The bill before you today would establish a limited loan forgiveness program as an incentive for medical students to become pediatric rheumatologists as well as several other incentives to address this shortage.

Almost 50 years ago, I was prescribed 24 aspirins a day to treat my disease. Today doctors have much more powerful therapies to treat kids. However, we still

have significant gaps in our understanding of what causes arthritis in kids and adults and we still have not discovered a cure.

Currently, the National Institutes of Health is spending only \$7 million on juvenile arthritis research. This is out of a \$28 billion budget. This means that our government spends only \$23 a year on research per every child with arthritis.

The bill before you today would authorize the NIH to make juvenile arthritis research a higher priority and intensify funding to find a cure. It is critically important that this happen if we are to help these children.

Arthritis is a difficult and complicated disease. My story is proof of that fact. Winning the war against arthritis will require bringing together our best and brightest minds and the efficient use of taxpayer dollars as we seek to fund the best research, build a strong public health response, and ensure persons with arthritis have access to the care and medicines they need.

The legislation would authorize the Secretary of Health and Human Services to establish an Arthritis and Rheumatic Diseases Interagency Coordinating Committee. This group would be charged with convening a Summit of researchers, public health professionals, Federal agency representatives, voluntary health agencies and professional and academic groups to review current NIH research activities and recommend future areas of collaboration between Federal agencies. This work is critically important as we seek to improve the lives of children and adults living with this disease.

In closing, I want to extend my deep thanks to Senators Bond and Kennedy for introducing this landmark legislation. I hope that my story inspires other members of the Senate to co-sponsor this bill.

Thank You.

Senator BOND. Now we turn to Dr. Rothman.

STATEMENT OF DEBORAH ROTHMAN, PH.D., M.D., AMERICAN COLLEGE OF RHEUMATOLOGY, SPRINGFIELD, MA

Dr. ROTHMAN. Thank you, Chairman Bond, Ranking Member Mikulski, and all of the Members of the Subcommittee, for providing me with this opportunity to testify on behalf of children with arthritis. I would also like to thank Senators Bond and Kennedy for introducing the legislation that I intend to focus my remarks on today.

I am a member of the American College of Rheumatology, an organization of over 7,000 members dedicated to helping take care of people with musculoskeletal disease. It is an honor to be here today.

My name is Deborah Rothman. I am a pediatric rheumatologist. I take care of children with arthritis. There are only 192 pediatric board-certified pediatric rheumatologists in the United States today, so I may be the first one and the only one that many of you have ever seen. I am fortunate to practice at the Shriners Hospital for Children in Springfield, MA.

People are often surprised to learn that very young children can get arthritis. In the United States today, nearly 300,000 children under the age of 17 are afflicted by juvenile arthritis. Many of my patients became ill when they were less than 3 years old.

There are different types of childhood arthritis, but they all have one thing in common: swollen, painful joints that make it hard for children to walk, run, and play. Their social development and their educational achievement may be affected. Their growth is often impaired, and their bodies may become deformed if they do not get proper treatment. Many of these children require frequent hospitalizations.

I know my time here is limited today. With your permission, Chairman Bond, instead of telling you more about JRA, I would like to show you. I have great videos. The person running the

equipment is my boss. This is Dr. Peter Armstrong. He is a pediatric orthopedic surgeon, and he is the chief medical director of all 22 Shriners Hospitals in the United States, Mexico, and Canada.

In one second, I am going to ask him to start it running. For purposes of time, we have edited them down. What you are going to see on three of the children are their before and after videos—before meaning that these were taken within a day or two of first coming to see me at Shriners Hospital; the after videos, which will be—the before and after are each about 30 seconds. The after videos are anywhere from a week to 6 months after their initial assessment. The final video is one that we just put in. I saw this child in my clinic on Monday morning right before I got on the plane. She is a 19-month-old girl and has been treated for 6 months by adult rheumatologists and no pediatric rheumatologist. It took her 6 months and it was a 4½-hour car trip to come see me at Shriners. So if Dr. Armstrong could start that.

[Videotape shown.]

Dr. ROTHMAN. Just play close attention to how these children are walking. This is a child who only has one joint involved, but was this way for several years before she was seen. Here she is after intensive aggressive therapy and treatment. She is very happy. [Laughter.]

The next one is a little girl with poly-JRA. She lives in a small town in Vermont. She was symptomatic for over a year. You can see how hard it is for her to walk. Every joint hurts. She is stiff, she is sore, she is miserable. You are going to see her after in one second. She received a new medication, and you can see that it has truly given her a life.

The next one is a boy who was sick for 5 years, never saw a pediatric rheumatologist. You can see that he has trouble getting out of the chair. He can only walk with crutches, and even then with problems. His hips, his knees, one ankle, an elbow, and a thumb are affected by this. The physical therapist is lifting up the jacket so you can see. Here he is after treatment with a new medication and joint injections and traction. I don't know if you can tell. He is smiling.

This is a child I saw who has been symptomatic for over 6 months, and Monday was the first time she ever saw a rheumatologist. Her left knee is in fixed flexion at 40 degrees. She is affected in her left elbow, both wrists, and I think she is starting to brew something in her ankle.

I want to read you a letter that I received from the boy who you saw walking with crutches, and then you saw him just walking with his cane as an accessory.

"Thank you for your help. Now I have the medicine I need to get better. I've been sick for 5 years and until now the doctors did not know what was wrong with me. In the last 10 months the pain got worse and I could hardly walk. Thanks to the new medicine I can walk again."

Why did it take so long for these children to get the help they needed? There is a critical shortage of pediatric rheumatologists. Fourteen States in our great land do not have any pediatric rheumatologists. Mr. Chairman, in your home State of Missouri, there are only four. In my State of Massachusetts, we are fortunate enough to have 10, but most of them practice in Boston. There are

none in Maine. The States of New Hampshire and Vermont share one part-time pediatric rheumatologist. Some of my patients from New England travel over 4 hours for their clinic appointments. Nearly half of all medical schools in the United States do not have a pediatric rheumatologist. Of the fellows currently in training to become pediatric rheumatologists, 40 percent of them are from abroad and will return to their own countries.

The ACR, therefore, strongly supports section 6 of the Arthritis Prevention, Control, and Cure Act, investment in tomorrow's pediatric rheumatologists. We commend your attention to the critical need of an increased pediatric workforce by including in the bill incentives to encourage medical students and residents to enter the field of pediatric rheumatology. The bill would establish a pediatric rheumatologist loan repayment program through the Health Resources and Services Administration.

Section 6 of the Arthritis Prevention, Control, and Cure Act would also increase the number of career development awards through NIH for health professionals who intend to build careers in clinical and translational research relating to pediatric rheumatology.

Training more pediatric rheumatologists is just a beginning. We do not yet know what treatments are the safest and most effective for children. This is because research for childhood arthritis desperately needs funding to study the causes, treatments, and natural history of the various forms of juvenile arthritis. The studies done in hospitals and universities show that childhood arthritis differs dramatically from adult rheumatoid arthritis. Multi-institution studies are needed to truly understand these distinct pediatric diseases and to find the best and safest treatments to control each of them.

The pediatric rheumatologists in the United States have formed a research network, the Childhood Arthritis and Rheumatology Research Alliance, called CARRA, of which I am a member. This is a collaborative group formed to study juvenile arthritis in its many forms. We are working to understand the causes and to find the best treatments for children with arthritis. Our vision is to change the outcome of juvenile arthritis in as profound a way as the Childhood Oncology Group has changed the prognosis in pediatric leukemia and many other cancers.

Other pediatric disease networks have Federal funding. This is not the case for researchers and physicians caring for children with arthritis. We also need to collect data on the outcomes associated with juvenile arthritis. Right now, when a parent of a child with arthritis asks me what the future holds, I am unable to answer. Section 5 of the Arthritis Prevention, Control, and Cure Act would increase funding for innovative research in juvenile arthritis and to study outcomes associated with juvenile arthritis at the CDC. This is strongly supported by the ACR.

I thank the subcommittee for recognizing that arthritis is a serious national health problem. The legislation before us today represents an important milestone in efforts to improve our understanding of what causes arthritis and ensuring that all Americans, young and old, have access to the care they need. The American College of Rheumatology looks forward to being a partner with you

to help improve the lives of persons with the Nation's leading cause of disability.

Thank you.

Senator BOND. Thank you, Dr. Rothman.

[The prepared statement of Dr. Rothman follows:]

PREPARED STATEMENT OF DEBORAH ROTHMAN, PH.D., M.D.

Thank you, Chairman Bond, Ranking Member Mikulski, and all of the Members of the Subcommittee, for providing me the opportunity to testify on behalf of children with arthritis. It is an honor to be here today. My name is Deborah Rothman. I am a board-certified pediatric rheumatologist. I take care of children with arthritis. There are only 192 pediatric rheumatologists in the United States today so I may be the first one you've ever seen. I am fortunate to practice at Shriners Hospital for Children in Springfield, Massachusetts.

On behalf of the 7,000 members of the American College of Rheumatology (ACR), I would like to thank Senators Bond and Kennedy for introducing the legislation I intend to focus my remarks on today, the Arthritis Prevention, Control, and Cure Act of 2004.

The ACR is an organization of physicians, health professionals and scientists that serves its members through programs of education, research and advocacy that foster excellence in the care of people with arthritis, rheumatic and musculoskeletal diseases. As physicians involved in both research and specialized patient care, ACR members are acutely aware of the magnitude of the challenges that arthritis places on the health care delivery system.

Arthritis means swelling, pain and loss of motion in the joints of the body. There are more than 100 rheumatic diseases that cause this condition, which can sometimes be fatal, in both children and adults. One in three adults, or 70 million people in the United States, is affected by arthritis and other rheumatic conditions. Arthritis and other chronic joint problems are the leading cause of disability among adults in the U.S., costing more than \$86 billion a year in medical costs and lost productivity. This burden will surely increase as the baby boomers continue to age.

Rheumatologists are internists or pediatricians who are uniquely qualified by additional training and experience in the diagnosis and treatment of arthritis and other diseases of the joints, muscles and bones. Rheumatologists are highly skilled in the clinical detective work necessary to discover the cause of swelling and pain. Typically rheumatologists act as consultants, determine diagnoses and recommend treatment plans to referring primary care physicians. When the patient is complicated, the rheumatologist may be asked to assume principal care of that patient. Typically a rheumatologist acts as a team leader coordinating the help of many skilled professionals including nurses, physical and occupational therapists, other subspecialty physicians when appropriate, psychologists and social workers. Health care professionals can help people with musculoskeletal diseases and their families cope with the changes the diseases cause in their lives. Many rheumatologists conduct research to determine the cause, prevention and improved treatments for these disabling and sometimes fatal diseases. After 4 years of medical school and 3 years of training in either internal medicine or pediatrics, rheumatologists devote an additional 2 to 3 years in specialized rheumatology training.

You may be surprised to learn that very young children can get arthritis. In the U.S. nearly 300,000 children under the age of 17 are affected by juvenile arthritis. Many of my patients became ill when they were less than 3 years old. There are different types of childhood arthritis but they all have one thing in common: swollen, painful joints that make it hard for children to walk, run, and play. Their social development and their educational achievement may be affected. Their growth is often impaired and their bodies become deformed if they do not get adequate treatment.

I know my time is limited here today. So, instead of telling you more about juvenile rheumatoid arthritis, or JRA, I would like to show you. These are gait videos of three children with JRA before and after treatment. The first is of a little girl who has what we consider a mild form of JRA with only one joint involved. However, she did not receive appropriate treatment until she had been symptomatic for several years. You can see how hard it is for her to walk. The next video shows her after treatment. The next video shows a child with polyarticular JRA. She had symptoms for over a year before she was seen by a pediatric rheumatologist. You can see how stiff and uncomfortable she looks. The next video shows her after treatment. The last video shows an adolescent boy who had been symptomatic for 5 years before he was seen by a pediatric rheumatologist. You can see here he can barely

get out of his chair and needs crutches to walk. The final video shows him after treatment walking without his crutches or cane. This is from a letter he sent us:

“Thank you for your help. Now I have the medicine I need to get better. I’ve been sick for 5 years and until now the doctors did not know what was wrong with me. In the last 10 months the pain got worse and I could hardly walk. Thanks to the new medicine I can walk again.”

Why did it take so long for these children to get help? There is a critical shortage of pediatric rheumatologists. Fifteen States do not have any pediatric rheumatologists. Mr. Chairman, in your home State of Missouri there are only four. In my State of Massachusetts we are fortunate enough to have 10 but most of them practice in Boston. There are none in Maine and the States of New Hampshire and Vermont share one part-time pediatric rheumatologist. Some of my patients from New England travel over 5 hours for their clinic appointments. Nearly half of all medical schools in the United States do not have a pediatric rheumatologist. Of the fellows currently in training now, 40 percent of them are from abroad and will return to their own countries when they have completed their training.

The ACR is greatly concerned that there be an adequate future supply of both pediatric and adult rheumatologists to diagnose and treat arthritis patients of all ages. The ACR, therefore, is very supportive of section 6 of the Arthritis Prevention, Control, and Cure Act of 2004, investment in tomorrow’s pediatric rheumatologists. We commend your attention to the critical need for an adequate pediatric rheumatology workforce by including in the bill incentives to encourage health professionals to enter the field of pediatric rheumatology. The bill would establish a pediatric rheumatology loan repayment program through the Health Resources and Services Administration to provide loan repayment assistance to pediatric rheumatologists who agree to provide health care in an area with a shortage of pediatric rheumatologists.

Section 6 of the Arthritis Prevention, Control, and Cure Act would also increase the number of career development awards through the National Institutes of Health for health professionals who intend to build careers in clinical and translational research relating to pediatric rheumatology.

Training more pediatric rheumatologists is just a beginning. We do not yet know what treatments are the safest and most effective for children. This is because research for childhood arthritis desperately needs funding to study the causes, treatments, and natural history of the various forms of juvenile arthritis. The studies done in single hospitals or universities show that childhood arthritis differs dramatically from adult rheumatoid arthritis, but multi-institution studies are needed to truly understand these distinct pediatric diseases, and to find the best and safest treatments to control each of them.

The pediatric rheumatologists in the U.S. have formed a research network, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and are donating their time and energy to create this collaborative group to study juvenile arthritis in its many forms. They are working diligently to understand the causes, the different types of arthritis, and the best treatments for arthritic children. Their vision is to change the outcome of juvenile arthritis in as profound a way as the Childhood Oncology Group has changed the prognosis in pediatric leukemia and many other cancers. To do this, they need funding. Other pediatric disease networks, including specialists who care for children with cancers, immune deficiencies, juvenile diabetes, and the neonatologists who care for high risk newborns, all have Federal funding. This is not the case for researchers and physicians caring for children with arthritis. We also need to collect data on the outcomes associated with juvenile arthritis. Right now, when a parent of a child with arthritis asks me what the future holds I am unable to answer. Section 5 of the Arthritis Prevention, Control, and Cure Act would increase funding both for innovative research in Juvenile Arthritis and to study outcomes associated with juvenile arthritis at the CDC. This is strongly supported by the ACR.

Again, thank you for your commitment to fighting arthritis. The ACR believes the Arthritis Prevention, Control, and Cure Act of 2004 will have a tremendous positive impact on research into arthritis, as well as its diagnosis, treatment and eventual cure. In addition to emphasizing the importance of research on juvenile arthritis and encouraging more health professionals to enter into pediatric rheumatology, the bill would increase support for the important work of the Centers for Disease Control and Prevention’s (CDC) arthritis program and critical arthritis research at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and create more interaction between Federal agencies that work to address all forms of arthritis that affect both children and adults.

I am grateful for this opportunity to testify before the subcommittee today. I would be happy to answer any questions.

SHRINERS HOSPITALS FOR CHILDREN,
June 14, 2004.

Hon. BARBARA MILULSKI,
709 Hart Senate Office Building,
Washington, DC.

DEAR SENATOR MIKULSKI: Thank you for your support. Here is the information that you requested at the Senate Hearing on The Arthritis Prevention, Control and Cure Act of 2004.

I will address your concerns in the order they were presented.

Question 1. Who would do the epidemiologic survey of pediatric rheumatic diseases in the United States ?

Answer 1. The epidemiologic data that are required for better planning and improving services for children with rheumatic disease would be best coordinated by the CDC in partnership with CARRA (Childhood Arthritis and Rheumatology Research Alliance).

Question 2. What can we do now to help children with rheumatic diseases to ensure early recognition and referral to a pediatric rheumatologist as well as providing comprehensive care?

Answer 2. There needs to be outreach and educational programs for pediatricians, family practitioners, adult rheumatologists, and orthopedists who practice in areas without pediatric rheumatologists. There is a successful program designed by Helen Emery, M.D. (Seattle WA) in Northern California that has been funded by the Arthritis Foundation summarized briefly here: Pediatric rheumatologists travel to underserved areas and conduct workshops to train community physicians to identify and diagnose children with rheumatic disease. Through these face-to-face meetings a clinical network is created providing the local physicians with access to pediatric rheumatologic expertise for advice and referral when needed. Pediatric rheumatology centers will be able to coordinate ongoing care with local community physicians. This program can also be used for the nearly half of all medical schools that do not have a pediatric rheumatologist on faculty with an additional component for medical student and resident teaching, including residents in pediatrics, orthopedics, family practice, and osteopaths.

The comprehensive care needed by these children requires additional funding for ancillary services including social services, nursing, transportation, occupational and physical therapy, and nutrition. Nurses, nurse practitioners, and physicians' assistants will also be needed to provide the additional manpower to allow the pediatric rheumatologists time to teach these outreach educational programs and to manage the increase in patient referrals and coordinated care resulting from the creation of these regional clinical networks.

Approximate financial commitment: \$250,000/center/year \times 50 centers = \$12,500,000/year.

Funding for the clinical year for an additional 12 pediatric rheumatology fellows would also provide direct care for children with rheumatic disease. The clinical year of the 3-year pediatric rheumatology fellowship is devoted entirely to patient care and is not funded by any current mechanism, whereas the second and third year can be supported by research grants. Many fellowship programs cannot take fellows because they cannot support the clinical training year.

Approximate financial commitment: 12 fellows \times 70,000/year = \$840,000/year

Question 3. What does CARRA need? (Childhood Arthritis and Rheumatology Research Alliance)

Answer 3. The mission of CARRA is to facilitate, and conduct high quality clinical research in the field of pediatric rheumatology. A clinical research network can directly lead to advancements in therapies, resulting in improved outcomes as shown by the Children's Oncology Group (COG). Since its creation 3 years ago, CARRA has gathered the leading researchers and clinicians in pediatric rheumatology to create a network that includes most pediatric rheumatologists in North American and over 70 institutions. CARRA has designed a network structure that is based on regional centers (hubs) which support the affiliated smaller pediatric rheumatology programs and community physicians in each region to coordinate and perform clinical research studies. There are 2 critical steps necessary for CARRA's success over the next 3-5 years. The first is to support physician scientists who will design the stud-

ies needed to answer the important questions, write grants to funding agencies such as NIH and the Arthritis Foundation, and analyze and publish the results in the medical literature. The second part is to support the regional hubs and the many pediatric rheumatology sites that are required to recruit patients and implement the clinical trials.

CARRA and the clinical network developed in the previous question will work together. CARRA can bring state-of-the-art care to any patient that has access to a CARRA site and the clinical network can work in the local communities to recruit patients. This support would enable the CARRA members to conduct multicenter research and drug studies funded by a variety of resources including NIH, national foundations (such as the Arthritis Foundation, Alliance for Lupus Research), and pharmaceutical companies.

Question 4. Who would fund CARRA?

Answer 4. Funding for the CARRA infrastructure should come from the NIH, similar to the Children's Oncology Group. The institutes that could be involved are NIAMS, NICHD and NIAID. Funding should be ramped up over 3–4 years to reach the following levels by Year 4:

- \$4.6 million/year for the structure described.
- Creation of a data base to follow all children treated with medications with oncologic potential, as well as other complications, for long-term outcome studies.

Question 5. What is the role of the FDA?

Answer 5. The majority of childhood rheumatic diseases are rare so medications used to treat them are not included under the pediatric rule. All medications that may be used to treat pediatric rheumatic diseases must be tested in children. As you know, there are many organizations doing work in this area who would have constructive suggestions. The comments here represent a preliminary consensus among the pediatric leadership of the American College of Rheumatology, the Arthritis Foundation, and CARRA.

I appreciate your interest and the significant questions that you are asking about pediatric rheumatology.

Sincerely,

DEBORAH ROTHMAN, PH.D., M.D.

Senator BOND. Dr. Klippel.

STATEMENT OF JOHN H. KLIPPEL, M.D., PRESIDENT AND CHIEF EXECUTIVE OFFICER, ARTHRITIS FOUNDATION, ATLANTA, GA

Dr. KLIPPEL. Thank you, Mr. Chairman.

It is a great privilege and honor for me to testify this morning on behalf of the Arthritis Foundation.

It is also a great privilege and in fact humbling to share our testimony with KaLea Kunkel and Virg Jones. We applaud their courage for speaking up, and we value their partnership.

The Arthritis Foundation is the voice of 70 million Americans with arthritis or chronic joint symptoms, including 300,000 children with arthritis.

The legislation before us today represents a significant step in our fight against arthritis. I will focus on several key elements in the bill, beginning with arthritis and public health.

In 1998, the Arthritis Foundation, the Centers for Disease Control and Prevention, and more than 50 national organizations partnered on the first ever national public health strategy addressing arthritis—the National Arthritis Action Plan, or NAAP. The plan represents an ambitious effort to increase awareness about arthritis prevention and the greater use of evidence-based self-management strategies. It seeks to expand our knowledge of risk factors and the impact of arthritis, and the burden the disease places

on our society and economy as we build our public health infrastructure through the formation of State and local partnerships.

The launch of the NAAP has already led to several major accomplishments, the most important of which is the establishment of an arthritis program at the CDC, and the inclusion of several goals specifically related to arthritis in Healthy People 2010.

In 1998, there was only one-half of one full-time position dedicated to arthritis at the Centers for Disease Control. Under the leadership of Dr. James Marks at the agency, and consistent with the goals of the NAAP, this condition has changed dramatically.

CDC has established a highly successful arthritis program that supports arthritis prevention, leads the Nation's arthritis surveillance efforts, and has resulted in the development of arthritis public health programs in 36 States. This is an extraordinary record of accomplishment in a relatively short period of time, and the Arthritis Foundation is extremely proud to partner with this agency in this effort.

Healthy People is the Nation's public health blueprint.

The 2010 Healthy People Plan contains an entire chapter devoted to arthritis. It sets national goals on reducing the pain and physical limitations faced by people with arthritis. It sets goals on reducing health disparities that currently exist with many minority populations. In particular, it addresses the problem of the disparity with African Americans and the rest of the Nation in the area of total knee replacement surgery.

Yet our Nation continues to face an epidemic of arthritis. As indicated earlier by Dr. Sniezek, 49 million Americans have doctor-diagnosed arthritis, and an additional 21 million have chronic joint symptoms and have yet to see a health care provider.

With the aging of the baby boomers, the CDC predicts that the number of people over the age of 65 with arthritis and chronic joint symptoms will double by the year 2030.

Obesity, lack of physical activity, and premature cardiovascular disease are significant and modifiable risk factors for persons with arthritis and for people at risk for developing arthritis.

Young women with diseases like rheumatoid arthritis and lupus die early. The cause of their death is cardiovascular disease.

Osteoarthritis is the most common single form of arthritis. People normally associate this with aging. However, children and teenagers who are overweight and who do not engage in physical activity are more likely to develop osteoarthritis as they grow older. Similarly, joint injury in children and teenagers from rugby poses a similar risk for the early development of osteoarthritis.

Senator BOND. Now you tell me.

Dr. KLIPPEL. We are seeing persons as young as 20 and 30 years of age develop osteoarthritis. This Nation is indeed facing a crisis.

This legislation would expand on the NAAP in two important areas. It would establish a national awareness initiative focused on ensuring that we meet or exceed the national objectives in Healthy People 2010. Second, it would address a significant gap in our understanding of arthritis among children by authorizing a national prevalence study on the impact of arthritis in children.

Congress showed exceptional vision and leadership by doubling the research budget of the National Institutes of Health. The Ar-

thritis Foundation is extremely proud of the role that we played in the creation of the National Arthritis, Musculoskeletal and Skin Diseases Institute at the National Institutes of Health. This unprecedented action represents the single largest and most significant investment in the health of mankind ever seen.

However, not all areas of research have benefitted equitably from the dramatic increases in taxpayer support. For example, Congress appropriated \$28 billion for the NIH in fiscal year 2003. Of these dollars, only \$7 million was spent on juvenile arthritis research. When measured per child with arthritis, this equates to \$23 per child.

As a researcher, I understand the critical importance of funding research to acquire new knowledge that will help to provide more effective and safer approaches to treatment and eventually, ways to prevent and cure the disease. This legislation seeks to increase our investment in research to find a better solution to the serious problems facing everyone with arthritis, including children.

Under the bill, at least two planning grants will be awarded to collaborative public-private partnerships to plan, establish and improve upon existing or new arthritis programs. I believe these grants will begin to attract new researchers to this field and build greater research capacity to drive innovation.

The bill also authorizes the Secretary of Health and Human Services to convene an Arthritis and Musculoskeletal Coordinating Committee. This committee would host a national summit of the Nation's leading researchers, public health professionals, voluntary health association representatives, academic institutions, and Federal and State policymakers to provide a detailed overview of current research activities in the NIH as well as to solicit input related to potential areas of collaboration between NIH and other Federal agencies.

This effort would be a catalyst for the collaborative initiatives that are included in NIH Director Zerhouni's NIH Road Map Initiative. In the spirit of the Road Map, the legislation will help to spark new and innovative research efforts, support cross-discipline research partnerships which better address the needs of people with arthritis in such areas as pain research, obesity, and cardiovascular disease, and would ensure that we continue to be good stewards of limited Federal research dollars.

In 1975, Senator Alan Cranston of California introduced the last major piece of arthritis legislation. It was signed into law by President Gerald Ford. The bill, the National Arthritis Act, set our Nation on an important path in the fight against arthritis. It led to the creation of an institute at NIH of which we are all extremely proud, focused on arthritis, and laid the foundation for a national arthritis public health strategy.

I can say with confidence that these actions have profoundly changed the lives of people like KaLea Kunkel and Virg Jones and millions of others. However, arthritis is still claiming the lives of millions of Americans, causing them terrible pain, disability, and premature death.

I applaud both you and Senator Kennedy and other cosponsors of the bill for recognizing this silent problem that for far too long

has been neglected. We thank you for taking a leadership role on behalf of people like KaLea and Virg.

The Arthritis Foundation will continue to advocate for passage of this important legislation, which will set the Nation on a path toward a better life for people with arthritis and eventually, a cure.

Thank you.

Senator BOND. Thank you very much, Dr. Klippel, and my thanks to the entire panel for very compelling testimony.

[The prepared statement of Dr. Klippel follows:]

PREPARED STATEMENT OF JOHN H. KLIPPEL, M.D.

Thank you Mr. Chairman, Ranking Member Mikulski, and all of the Members of the Subcommittee for hosting today's hearing and for inviting me to testify on behalf of the Arthritis Foundation. I would also like to thank Senators Bond and Kennedy for their leadership in introducing the Arthritis Prevention, Control, and Cure Act, which will be the focus of my remarks today.

My name is Dr. John Klippel and I'm President and CEO of the Arthritis Foundation. I've been with the Foundation for the past 5 years, four of them as the Foundation's Medical Director. Prior to joining the Arthritis Foundation in 1999, I served as Clinical Director at the National Institute of Arthritis, Musculoskeletal and Skin Diseases at the National Institutes of Health. I'm an arthritis researcher and rheumatologist.

The Arthritis Foundation is the voice of 70 million Americans with arthritis or chronic joint symptoms, including 300,000 children with arthritis. We are the single largest non-profit funder of arthritis research in the world, and the largest nationwide, nonprofit health organization dedicated to the prevention, control and cure of arthritis—the Nation's number one cause of disability.

The legislation before us today represents a significant step in the fight against arthritis. I will focus on several key elements in the bill, starting with arthritis and public health.

In 1998, the Arthritis Foundation, the Centers for Disease Control and Prevention, and more than 50 national organizations partnered on the first-ever national public health strategy addressing arthritis—the National Arthritis Action Plan (NAAP). The plan represents an ambitious effort to increase awareness about arthritis prevention and evidence-based, self-management strategies. It also seeks to expand our knowledge of risk factors and the impact of arthritis, and the burden the disease places on our society and economy, as well as build our public health infrastructure through the formation of State and local partnerships.

The launch of the NAAP has already led to several major accomplishments. The most important are the establishment of an arthritis program at the CDC, and the inclusion of several goals specifically related to arthritis in the Healthy People 2010 goals for the Nation.

In 1998, there was only one-half of one full-time position dedicated to arthritis at CDC. Under the leadership of Dr. Jim Marks at the agency and consistent with the goals of the NAAP, this condition has changed significantly. CDC has established a highly successful arthritis program that supports prevention research, leads the Nation's arthritis surveillance efforts, and resulted in the development of arthritis public health programs in 36 States. This is an extraordinary record of accomplishment in a relatively short period of time, and the Foundation is proud to be a partner with the agency in this effort.

Healthy People is the Nation's public health blueprint. Healthy People 2000 contained very little about arthritis. The 2010 plan contains an entire chapter devoted to arthritis. It sets national goals on reducing the pain and physical limitations faced by people with arthritis. It sets goals on reducing the health disparities that currently exists between African Americans and the rest of the Nation in the area of total knee replacement surgery.

Yet, our Nation continues to face an arthritis epidemic. As CDC stated earlier, 49 million Americans have doctor-diagnosed arthritis and 21 million may have arthritis. With the aging of the baby boomers, CDC predicts the number of people over 65 with arthritis or chronic joint symptoms will double by 2030.

Obesity, lack of physical activity and premature cardiovascular disease are significant and modifiable risk factors for persons with arthritis and people at risk for developing arthritis. For example, on average, a young woman diagnosed with rheumatoid arthritis will die 10 years before a person who does not have the disease. She will not die from RA, but rather from cardiovascular disease.

Osteoarthritis is the most common form of arthritis that people normally associate with old age. However, children and teenagers who are overweight and do not engage in physical activity may be more likely to develop osteoarthritis as they grow older. Similarly joint injury in children and teenagers poses a similar risk for the early development of osteoarthritis. We are now seeing persons as young as 20 and 30 years old develop osteoarthritis.

This legislation would expand on the NAAP in two important areas. It would establish a national awareness initiative focused on ensuring we meet or exceed the national objectives in Health People 2010. Second, it would address a significant gap in our understanding of arthritis among kids by authorizing a national prevalence study on the impact of arthritis in children.

Next, I'll address the area of biomedical research and arthritis. Congress showed exceptional vision and leadership by doubling the research budget at the National Institutes of Health. This unprecedented action represents the single largest and most significant investment in the health of mankind ever seen. However, not all areas of research have benefited equitably from the dramatic increases in taxpayer support.

For example, Congress appropriated \$28 billion for NIH in fiscal year 2003. Of these dollars, only \$7 million was spent on juvenile arthritis research. In 2001, total NIH funding for juvenile arthritis research reached a low of \$2.8 million.

When measured by child with juvenile arthritis, this means \$23 per child.

As a researcher, I understand the critical importance of funding research to acquire new knowledge that will help to provide more effective and safer approaches to treatment of arthritis, and eventually ways to prevent and cure the disease. I also recognize the important responsibility to develop innovative solutions to circumstances where we lack research capacity to answer fundamental questions about a painful and disabling disease. Merely saying that there weren't enough quality research grants is not an appropriate answer.

This legislation seeks to increase our investment in research to find a better solution to the serious problems facing children with arthritis. Under the bill, at least two planning grants will be awarded to collaborative public/private partnerships to plan, establish and improve upon existing or new research programs focused on innovative approaches to the treatment of juvenile arthritis. I believe that these grants will begin to attract new researchers to this field and build greater research capacity to drive the necessary innovation.

The bill also authorizes the Secretary of Health and Human Services to convene an Arthritis and Musculoskeletal Coordinating Committee. A proven strategy in other disease States, this group would host a national summit of the Nation's leading researchers, public health professionals, voluntary health association representatives, academic institutions, and Federal and State policy makers to provide a detailed overview of current research activities of the NIH, as well as to solicit input related to potential areas of collaboration between NIH and other Federal agencies.

It would focus on research areas critically important to progress in arthritis including basic biomedical research directed at better understanding of arthritis, translational (bench to bedside) research, epidemiological, psychosocial and rehabilitative issues; clinical research on development of new treatments; information and education programs for health professionals and the public; determination of research priorities for federally-supported initiatives; and address the challenges and opportunities faced by the research community and public.

This effort would be a catalyst for the collaborative initiatives that are included in NIH Director Zerhoni's NIH Roadmap Initiative. In the spirit of the Roadmap, this legislation will help spark new and innovative research efforts, support cross-discipline research partnerships, which better address the needs of people with arthritis, in areas of pain research, obesity, and cardiovascular disease, and would ensure that we continue to be good stewards of limited Federal research dollars. This focus may lead to more solutions to the challenges facing juvenile arthritis research as well as the myriad of other challenges facing NIH and partnering Federal agencies like CDC, the Food and Drug Administration, and the Agency for Healthcare Research and Quality.

In 1975, Senator Alan Cranston of California introduced the last major piece of arthritis legislation. It was signed into law by President Gerald Ford. The bill, the National Arthritis Act, set our Nation on an important path in the fight against arthritis. It led to the creation of an institute at NIH focused on arthritis, and laid the foundation for a national arthritis public health strategy.

I can confidently say that these actions have profoundly changed the lives of people like KaLea Kunkel and Virg Jones and countless others. However, arthritis is still claiming the lives of millions of Americans, causing them terrible pain, disability, and premature death.

I applaud Senators Bond and Kennedy and the other cosponsors of the bill for recognizing a problem that for far too long has been neglected and for taking a leadership role on behalf of people like KaLea and Virg. The Arthritis Foundation will continue to advocate for passage of this important legislation, which will set this Nation on the path toward a better life for people with arthritis and eventually a cure.

Thank You.

Senator BOND. Going back to KaLea, everybody is talking about physical activity being helpful. Are you able now to engage in physical activity, and do you have a regimen that is helpful in your particular case?

Ms. KUNKEL. Yes. I started swimming through a program with the Arthritis Foundation. They began a program I do not know how many years ago for children and I believe also adults with arthritis so they could learn joint exercises to help keep up their mobility. I started that in my first couple years of elementary school, and it taught me all these new strokes. Since then, I have loved swimming, and still today I notice a difference when I am out of the pool on how well my knees and my hips function, my shoulders. If I am out for very long, I begin to have more joint problems.

The activity that they helped us learn, still today, I use. If I have more joint pain, I find myself doing those exercises in the pool and in the water, sometimes in the bathtub, to help with the joint pain.

Also, I think the physical activity helps with your mental outlook over your disease, because it keeps you functional, which I think keeps up your attitude about it, and in my experience, one of the best things that you need to do is to remain functional and have a good outlook on it, because without it, the disease would be even worse, and I think it encourages that a lot, so it has been very beneficial.

Senator BOND. Virg, do you have any physical activity that is helpful in your case?

Mr. JONES. Well, I am kind of the herald that carries the banner for the water exercise programs of the Arthritis Foundation. The 6 years I was in the hospital, we had to get into hot water every day for exercise, and I never liked the exercise, but I did like the water. But since I got out of the hospital, and when I retired from the Federal Reserve System in 1994, I started swimming. I am an avid swimmer. I have a pool at my house, and during the summer, I swim an average of 7 to 10 miles a week—that is at least 2 hours a day. During the winter, I swim at a community center and try to go three times a week and swim for an hour.

But I tell everybody I meet who has arthritis to get in the pool. There is no excuse. If you do not like the water, get in there anyway, because what I have found—of course, all my joints are destroyed; I do not have any cartilage, I do not have any rotator cuffs or anything like that that are in good shape—but swimming, and maintaining some range of motion and mostly muscle tone helps more than anything else. I have learned that no matter how hard I press myself, the more I can maintain the muscle and the cardiovascular system, the better I feel. I think it is just so important that all people who have arthritis get access to warm water therapy.

Senator BOND. Thank you, Virg.

Dr. Rothman, you made some amazing strides with those patients that you had. Has this come about in the last 10 years or

so? What are the exciting new things that are making such a profound impact?

Dr. ROTHMAN. I think we have gotten much more aggressive about treating these children. I finished my fellowship in 1994. From that time until now, there have been absolutely extraordinary developments. One of the most important has been the use of cytokine blockade. That would be a way to decrease the inflammation in children.

You have heard of these drugs called etanercept and remicaid. The two children who showed the most extraordinary improvement both received etanercept. The boy whom you saw getting out of the wheelchair and then the after picture—the after was 2 weeks after he started etanercept. He had also been treated in our orthopedic hospital by joint injections with steroids, which have made a huge difference in children. He had also been put in traction for a week to stretch out his muscles; he was very contracted.

But I would say that in my experience, etanercept and remicaid have absolutely turned the course for some children but not all. We still do not have good treatment for systemic-onset JRA, which is the type of arthritis with high fever, systemic organ involvement. Those children are helped by the medicines oftentimes, but not to the same degree as children with polyarticular arthritis.

The other thing that we have learned from our colleagues in oncology is that many of these children need multi or combination therapy, so these children will be on two or three or four drugs at once. They will receive high-dose steroids intravenously on a regular basis. They are frequently hospitalized—we refer to these children with great affection as our “frequent fliers.” They need a lot of care and ongoing, and we are very aggressive about therapy, we are very aggressive about getting them active.

Senator BOND. Thank you.

Dr. Klippel, you talked about the cardiovascular disease leading to premature death in people with arthritis. What is the relationship between cardiovascular disease and arthritis?

Dr. KLIPPEL. Well, Senator, thanks to the cover of Time Magazine, I think the American public was taught that inflammation is a key risk factor for atherosclerosis.

What we have known for years is that people with some of the most serious forms of arthritis, like rheumatoid arthritis and lupus, develop cardiovascular disease early. So we believe it is the systemic inflammation and the attack of the immune system which is responsible for their underlying disease that contributes to this. We believe that that provides an opportunity for us to more effectively work with cardiovascular disease researchers to better understand atherosclerosis, to help our own patients as well as anyone in this Nation who suffers from atherosclerosis.

Senator BOND. So Vioxx would have cardiovascular benefits, perhaps?

Dr. KLIPPEL. Well, that is an interesting question, because what we know is that COX-2, which is one of the enzymes involved in inflammation, certainly can play a role in heart disease, and I think there is a lot of research that needs to be done to better understand the detailed mechanisms of atherosclerosis and how we more effectively use not only drugs, but I think other preventive

strategies like obesity management, physical exercise, as a way to benefit for atherosclerosis and arthritis.

Senator BOND. Is there any other step? You have mentioned a number of things. What do you see from the Foundation's standpoint as additional steps that appear promising?

Dr. KLIPPEL. Well, I think several things—the Foundation is committed to getting the best and brightest minds in this country to dedicate their lives to arthritis, whether it is research or the provision of care. So we do want to invest in young people so that there will be a manpower force that can actually solve this problem and care for people with arthritis.

We are committed to three things. We are committed to investing our resources in research and working with others who share that vision. We are committed to public health. We believe that the launch of public health initiatives is an extremely important strategy to address the problem of arthritis.

Finally, we are privileged to work with you, because we recognize that many of the challenges faced by people with arthritis are only going to be solved through legislative and policy initiatives, so that you play an extremely valuable role in working with us to improve the lives of people with arthritis.

Senator BOND. Thank you very much, Dr. Klippel.

Senator Mikulski.

Senator MIKULSKI. Thank you, Mr. Chairman.

First, to Ms. Kunkel and Mr. Jones, thank you for your very poignant and compelling testimony. I think the words that I would like to use are “courage” and “determination.”

First of all, I want to thank you for your public advocacy and the fact of the trauma that you went through not only from the disease but being able to have a life, a social life, et cetera. The fact, Ms. Kunkel, that you are in college, and Mr. Jones finished college and was able to make a contribution and raise a family, is a tribute first of all to your grit. So we thank you for what you said.

It also brings up another issue of caregiving, which we have not discussed here, and the caregiver. First of all, Mr. Jones, where is Harriet?

Could Harriet stand up? Harriet, we want to give you a round of applause.

[Applause.]

I do not know if your mother is still with you, Mr. Jones, but God bless her for getting up those 2 hours early every morning.

Ms. Kunkel, is your family here with you today?

Ms. KUNKEL. My mother is here, sitting behind me.

Senator MIKULSKI. Let us hear your mother's name.

Ms. KUNKEL. I am sorry—Anne Kunkel.

Senator MIKULSKI. Let us give her a hand, too.

[Applause.]

Mr. Chairman, I think that is the subject of another hearing, which is caregiving for families where there are chronic situations, and of course, the first caregiver is always the family, and how we can support the family as they try to help people with really very severe chronic conditions. So we salute you.

Another topic would be the cost of insurance. As you have talked about, Dr. Rothman and Dr. Klippel, the hospitalizations, the pre-

scription drugs, the breakthroughs that we hope will come—it is great to have breakthroughs, but are we going to be able to afford to do it? Will the families be able to afford a prescription drug benefit? What we are seeing is that we are now struggling with a prescription drug benefit for seniors under Medicare, but if you have lupus, you tend to be in your thirties and forties, and you have talked about these wonderful children—that was like out of a miracle movie. I was so touched. We just wanted to cheer for those kids and give them T-shirts and pompons. It was just so wonderful to see that. But that is also another topic.

So just know that we want to be on your side and look at these issues.

Dr. Rothman, I want to come to your very compelling testimony. Ms. Kunkel raised the issue that there has been no prevalence study of this. Can you tell me who should do that and how we can get it?

Dr. ROTHMAN. I think there are other experts more qualified than I. My opinion would be that that is something that we need to work with with the CDC.

Senator MIKULSKI. I think this is another way that we can improve the legislation as it goes through markup, because I do think we need the basic tools of epidemiology and a prevalence study for juvenile arthritis as well as the various manifestations of it. Ms. Kunkel has one manifestation, other siblings had it, and the boys and girls in the very compelling videos.

So prevalence is number one.

Number two, let me get to your articulation about the need for pediatric rheumatologists, which Ms. Kunkel spoke to as well. We really want to support Section 6, so that is decided. But as we move legislation, the pipeline can take a while, and your own extensive training that you articulated. Are there ways now that we can encourage—or maybe it has no efficacy—ways that we can use pediatricians and others now. What you did there was really stunning for us to see, and thank you for bringing the video. But are there other ways that we can reach those people who treat children, not as a substitute, but as you know, it is going to be 3 years, 4 years, et cetera, where they have got to recruit, they have got to do these wonderful fellowships like you participated in, opportunities at places like Shriner's, but what can we do now—or do you think that that is of limited utility?

Dr. ROTHMAN. I think there are two issues, and that is a very good question. One possible solution or at least help would be if we can educate pediatricians and adult rheumatologists in communities. I will go anywhere and talk to anyone at any time about arthritis, and as part of Shriner's Hospitals, we do a lot of outreach clinics, we do a lot of teaching seminars so that pediatricians in not only our community but throughout know about the importance of early referral.

The other issue is that medical students and pediatric residents need to be exposed to rheumatologists, and there are some programs now for medical schools that do not have a pediatric rheumatologist on faculty, where a guest pediatric rheumatologist will go to the institution for 1 to 3 days, give lectures, see patients, and raise awareness.

I can tell you that the medical school I attended did not have a pediatric rheumatologist. I did not know the existence of the field until I did my residency at New England Medical Center. So I think we need to have residents being exposed.

Since I have been at Shriner's, we have actually had one pediatric resident become so interested in rheumatology that she is doing a fellowship starting this July at Duke University. I think that once pediatric residents get exposure to rheumatology, see how wonderful and amazing our patients are and learn about the diseases, they will want to go into it, because it is an amazing field to be in.

Senator MIKULSKI. Well, Doctor, first of all, let me say that in reading your testimony, it seems that so much of the efforts that you and your colleagues in pediatric rheumatology are—I do not mean making it up—but you are making up organizational efforts. When you talk here about the lack of a network and so on, I found this troubling, in the same way Dr. Klippel just talked about that out of the whole \$28 billion, we are spending \$7 million. That is beyond being skimpy.

I am going to then ask you, because the time is limited here, as you look to both the Academy and also the Foundation, to give us recommendations on, first, what should we be encouraging in terms of prevalence studies; second, how can we move thinking into other clinical areas of practice, just like you have said; and then also, your whole issue here about the fact that you do not have what you have in childhood oncology, which was this collaborative effort. Collaboration can also mean a lot of process, but it seems like practical minds and breakthrough minds are getting together to see what we can do.

You talk about Section 5 would increase the funding for innovative research—but you all need to talk with each other, and there need to be ways of encouraging—again, as you heard me earlier—with CDC to get what you all know into the physician's office while we are, again, absolutely committed to expanding the fellowship and other programs and seeing the implementation of Section 6.

Can you help us out here, where you would like to really improve the bill or put in report language, because it would seem to me that NIH and CDC should be doing a lot of this on their own, without us telling them what to do.

Dr. ROTHMAN. Could you be a little more specific in how you would like us to proceed?

Senator MIKULSKI. Well, first of all, I do not know what prevalence studies we have and what we do not have, so I am ready to write a letter or report language to say what should we get.

Number two, you in your own testimony on page 4 say that you formed a research network, the Childhood Arthritis and Rheumatoid Research Alliance, and you are donating your time. You say that this needs funding. Well, I am not sure what you are talking about. Is it in the legislation? Do we have to put in legislation? Do we have to direct funding—for you all to be you and to be the best that you can be and maximize and synergize the information.

So I am looking at that paragraph in your own testimony and would welcome insights on how you want to implement that.

Dr. ROTHMAN. I was on the telephone yesterday with one of the leaders of CARRA, Carol Wallace, and we were talking about a budget and exactly how much we would need—

Senator MIKULSKI. Where is that? Is that at NIH? Is that at CDC? Where is it?

Dr. ROTHMAN. CARRA is a separate organization, and we are trying to work in collaboration with all of these other organizations.

Senator MIKULSKI. But who would you get the money from?

Dr. ROTHMAN. We are in the process of applying for funds from the government.

Senator MIKULSKI. What government? You see, this is my whole point about the CDCs and the NIHS. Everybody is communicating and collaborating until you find out that maybe it is not working the way we all would like.

Dr. ROTHMAN. I will be on the telephone with several of the leaders of CARRA as soon as we are through with this hearing.

Senator MIKULSKI. You see, that is what I mean.

Dr. ROTHMAN. Yes. I will get a letter together for you with more specifics of what we need. I am not on the finance committee of CARRA, so I am not the best person to be addressing those questions to.

Senator MIKULSKI. But if CARRA is going to be CARRA, and you think this is important, then, that is it.

Dr. ROTHMAN. Yes.

Senator MIKULSKI. The other issue is also—and I again welcome your advice and insight as well as NIH, which goes to FDA and the whole issue of juvenile arthritic medications.

We have a wonderful colleague, Senator DeWine, who has really championed to be sure that we evaluate the pediatric implications of drugs, because taking something at age 70 is not the same as at the age of 7 or 47. We want to be sure again that we are getting the proper analysis at FDA.

Do you see where I am?

Dr. ROTHMAN. Yes, I do, and I am very honored that you agree with us that we absolutely need funding, and I understand that we need to get more specific information. That is simply something that I need to talk to my colleagues about.

Senator MIKULSKI. Why don't we do that? I know that our time is up. Then, the other is ideas on how we can encourage more information going out to pediatricians and adult rheumatologists, not as a substitute but as a way of at least bridging as we try to increase the number of people going into the field so that people like Ms. Kunkel and Mr. Jones do not have to drive 4 hours, with the tremendous strain on the families emotionally as well as on the budget.

These are compelling studies, and behind them, we know there are 300,000 kids, but we have got to start getting value for our dollar here.

So thank you, and Dr. Klippel, thank you for your work.

Senator BOND. Thank you very much, Senator Mikulski.

My sincere thanks to all of our witnesses today.

KaLea and Virg, you have really given us a new vision of how juvenile arthritis can be an all-consuming fact in your lives.

Dr. Rothman, you have given us hope that there are things that can be done.

Dr. Klippel, the work that you are doing, I know you have things that you need for us to do, but the impact of this disease on millions of Americans, with its costs, first maybe in dollars, but in human terms as well, is very, very significant.

I would welcome any suggestion specifically that any of you or even those in the audience may have about our bill. We appreciate the comments on the particular sections of the bill, and working together, I think there is a lot more we can do to ensure that Americans with arthritis in all of its forms have a better chance for a full and pain-free life.

We appreciate your work and thank you very much.

The hearing is adjourned.

[Whereupon, at 11:55 a.m., the subcommittee was concluded.]

